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THE STUDY OF LIVING KIDNEY DONOR DECISION-MAKING AND PSYCHOSOCIAL OUTCOMES
&
CLINICAL RESEARCH PORTFOLIO

Part One

(Part two bound separately)

YVONNE LOUISE MCNEILL

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology.

Faculty of Medicine Graduate School
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I dedicate this thesis to my three little children, Sean, Darcy and Michael, who made me laugh and gave me lots of hugs and kisses every day during a stressful time. To Darcy, a very big thank you for allowing Mummy to practice every cognitive assessment with you and for telling Mummy that all she had to do was try her best- I wonder where you heard that from? To Martyn, thank you for all your support and your tolerance of the tears and rants. I acknowledge that you did more than your fair share of cooking, shopping and bathing and bedding babies. To my Mum, a strong and independent women who worked very hard to give her daughters the education and opportunities she never had, just "thank you"- listing everything you have done would take up more pages than this thesis.

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CHAPTER 1: SYSTEMATIC LITERATURE REVIEW

A SYSTEMATIC REVIEW OF LIVING KIDNEY DONOR PSYCHOSOCIAL OUTCOMES.

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ABSTRACT

Background

Living kidney donation represents more than one in three kidney transplants in the UK. The medical outcomes for living donors are well known. However, there is limited research regarding the psychosocial outcomes for living kidney donors. Understanding the psychosocial outcomes of living kidney donation will facilitate informed consent and guide the development of services that maintain the long-term health of donors.

Aims

To systematically review prospective studies reporting on the quality of life of kidney donors following live kidney donation in comparison to quality of life pre- donation. To discuss the factors associated with poor psychosocial outcome.

Methods

All relevant computerised databases were search. Citations in all relevant publications were searched. Unpublished datasets were obtained from key researchers. Inclusion in this review was limited to English language publications and studies with a prospective study design.

Results

Thirteen articles meeting the inclusion criteria were reviewed. These studies indicated that live kidney donation causes short term changes in quality of life. However, for the majority of donors, postoperative quality of life does not differ significantly from preoperative quality of life and the changes are not clinically or socially relevant. Current and past psychiatric symptoms were found to be an indicator of psychosocial outcome following donation.

Conclusions

More research investigating the psychosocial outcomes of living kidney donors is required. Future studies should be of prospective design, should assess preoperative quality of life at a time reflecting premorbid functioning, and where possible, have a suitable comparison group.

1. INTRODUCTION

End-stage kidney disease (ESRD) is the complete, or almost complete, failure of the kidneys to function. The kidneys can no longer remove waste, concentrate urine, and regulate many other important body functions. Patients who have ESRD need dialysis[1] or a kidney transplant. Kidney transplantation is preferential because of superior quality of life and survival rates (Hariharan et al, 2000). Renal transplantation from a live donor poses the best outcome for individuals with ESRD. The survival rates for a living kidney graft at one year range from 88.8% to 93.9% in comparison to 75.7% to 87.7% for cadaveric[2] grafts (Hariharan et al, 2000). The mean lifespan for a living graft is also superior, on average 21.6 years in comparison to 13.8 years for a cadaveric graft (Hariharan et al, 2000).

The Human Tissue (Scotland) Act (2006) permitted donations from non-related donors and withdrew previous restrictions prohibiting individuals obtaining anything in return for donating and thus led to the introduction of new types of donor-recipient relationships; The non-directed altruistic donation involving donation to an unidentified recipient. The paired donation in which a donor who is incompatible with their chosen recipient donates to an anonymous recipient with whom they are more compatible, and in turn, the donor for this recipient donates to the original donors desired recipient. The pooled donation which is a similar process but involves three or more donor and recipient pairs. Consequently in the UK, the number of living donor kidney transplants is increasing – 475 in 2004-05, 589 in

[1] Dialysis is the artificial process of getting rid of waste and unwanted water from the blood.
[2] Kidney graft from a deceased donor.

2005-06, 690 in 2006-07, 831 in 2007-08, 927 in 2008-09 and 1,038 in 2009-10 – and now represent more than one in three of all kidney transplants (NHS blood and Transplant statistics).

The medical outcomes for living kidney donors has been well established. Kidney donors do not experience any long-term medical complications following donation; the life expectancy of donors is similar to that of non-donors and the risk of end stage renal failure does not increase (Ibrahim et al, 2009). The potential of having complications associated with the donation process is also low; the risk of death and serious surgical complications is 0.005% and 0.3% respectively (Nolan et al, 2004). However, research evaluating the impact of organ donation on the donors' psychological wellbeing is limited. It is imperative that the psychological outcomes for donors are investigated in order to facilitate informed consent and guide the development of services that maintain the long-term health of donors.

This review aims to systematically review prospective studies reporting on the psychosocial outcome of live kidney donors. There are two published reviews in this area, Clemens et al (2006) and Ku et al (2005). With respect to Clemens et al (2006) the author did not calculate effect sizes or present the results in table format to allow the reader to summarise and quickly compare the findings of the individual studies. Clemens et al (2006) also reviews both prospective studies and retrospective studies. Prospective studies identify study participants before donation and then compare their quality of life after donation with their pre-transplant quality of life and in some cases population norms. The study design allows the researcher to identify an exact period at which postoperative quality of life will be assessed. Retrospective studies identify individuals who have already donated and then ask them to report on their perception of their quality of life during the postoperative period. Such reports are then

compared to population norms. With a retrospective study design donors may have donated many years earlier and therefore their recall of the postoperative period may be subject to recall bias. Furthermore, comparing donors' postoperative quality of life to only population norms, as in the retrospective study design, introduces limitations. Several studies (Bergman et al, 2005; Smith et al, 2004 and Walton-Moss et al, 2007) have found that preoperatively donors score higher on quality of life rating scales than the general population. Thus it is possible that donation impacts negatively on donors' psychosocial health yet their scores on health-related quality of life questionnaires will remain comparable with population norms. Finally, since the publication of Clemens et al (2006) six prospective studies have been published (Aguiar et al, 2007; Minnee et al, 2008a and b; Pace et al 2003; Virzi et al, 2007; Walton-Moss et al, 2007). With respect to Ku et al (2005), the reviews limits itself to reviewing studies using the Short Form Health Survey (SF-36) (Ware et al, 1994) thus missing data from, Lumsdaine et al (2005), Minz et al (2005), Pace et al (2003) Simmons et al (1977), Taghavi et al (2001) Varma et al (1992), Yoo et al (1996). Since the publication of this study, seven studies of the psychosocial outcomes of living kidney donors have been published (Aguiar et al, 2007; Bergman et al, 2005; Kok et al, 2006; Minnee et al, 2008 a &b; Virzi et al, 2007; Walton-Moss et al, 2007). This study also reviews both prospective studies and retrospective studies. Furthermore, The Centre for Reviews and Dissemination suggest that it is essential to appraise the quality of the studies included in a review as this will impact upon the reliability of the results and therefore the conclusion drawn. Neither study has formally appraised the studies included in their review

2. METHOD

Aims

To systematically review prospective studies reporting on the quality of life of donors following live kidney donation in comparison to quality of life pre- donation.

Search criteria

The computerised databases searched were: Ovid Medline (1950-papers in process as of December 2010), Embase (1980- December 2010), Web of Knowledge Medline, EBSCO databases including IBSS, Medline, PsychInfo, PsychArticles, Psychology and Behavioural Sciences collection (1898-December 2010). Searches were limited to English language. Citations in all relevant publications were also searched.

The following terms were combined for electronic search:

- (live donor* or living donor* or living donation or live donation)
- (kidney or renal)
- (adaptation or social adjustment* or psychosocial* or psychological* or behavio*ral* or quality of life or activities of daily living or mental disorder* or depressi* or anxiety or mood disorder* or psychiatric diagnosis)

Inclusion criteria

- Studies reporting on postoperative psychosocial outcomes for live kidney donors
- Prospective design
- Postoperative outcomes compared to preoperative data.
- Unpublished data were included only if a subset of the data had been published in a peer reviewed journal
- English language.

Exclusion criteria

Qualitative studies, reviews with no new empirical data, conference abstracts and dissertations were excluded. In the case where authors had used the same dataset in more than

one publication, the reviewer included the whole dataset where obtained from the author or included the most recent publication.

Data on the number of days before live kidney donors returned to work were excluded because this outcome is influenced by many confounding factors such as type of employment, presence or absence of disability allowance and personal characteristics. Data on the length of hospital stay were excluded as this is influenced both by the surgeon who carries out the procedure and hospital policy. This review focuses on psychosocial outcomes for donors and therefore data reporting on the physical outcomes of donors are excluded. This includes physical component summary scale data from the SF-36 (Ware et al, 1994) and the World Health Organisation Quality of Life questionnaire. The one exception to this rule is that studies that reported the correlation between physical wellbeing and quality of life are discussed with the aim of understanding whether quality of life is affected by psychological wellbeing, physical disability or pain.

The quality of articles was assessed using a checklist derived from the Scottish Intercollegiate Guidelines Network (SIGN) guidelines for assessing the quality of cohort studies (SIGN 50). Articles were scored on the following criteria: Study rationale, sampling procedures, assessment method, consideration of confounding factors and statistical analysis. The total score was used to rank studies according to their methodological quality using the following criteria: <50% poor quality, 50-75 moderate quality, >75% good quality. A randomly selected twenty-five percent of the included studies were rated by a second researcher, who was a trainee Clinical Psychologist in their third year of training. Any minor discrepancies in quality rating were discussed in order to reach consensus.

A copy of the quality criteria data collection sheet can be seen in Appendix 2. Scoring for each article can be seen in Table 1. Table 2 details the quality ranking for each study.

Search Results

Seven papers were excluded from the review despite meeting the inclusion and exclusion criteria. Smith et al (2003) was superseded by Smith et al (2004) due to an overlap in the dataset. Minnee et al (2008a & b) were superseded by a larger dataset obtained from the author, thereafter referred to as Minnee et al (unpublished). Wolf et al (2001) was excluded because only the postoperative results were published and preoperative data could not be obtained from the author. Pace et al (2003) was excluded because although the study examined the psychosocial outcome of individuals who underwent a nephrectomy, the sample included individuals who underwent nephrectomy for medical reasons.
Details of the fourteen included studies are presented in Table 2.

Statistical Analysis

Effect sizes were recorded or calculated from the available data. Effects size was calculated using the Glass' method (Glass &Hopkins, 2008) whereby the effect size is calculated using the following equation: mean at follow-up subtracted by the mean at baseline divided by the standard deviation for the baseline. This method was chosen because the study by Smith et al (2003 & 2004) was the only prospective study to calculate effect size and did so using Glass's method. To maintain consistency and allow comparison between publications, further calculations were undertaken using the same method. Effect sizes were classified as follows: 0.2-0.49 equates to a small difference, 0.5-0.79 equates to a moderate difference and 0.8 or above equates to a large difference (Cohen, 1988).

The results of the SF-36 were also assessed using the following directive: a difference of 5-points in any domain was considered minimally clinically and socially significant and a difference of ten-points was considered moderately clinically and socially significant (Ware et al, 1994).

Where publications presented their results in graph or boxplot format (Kok et al, 2006; Lumsdaine et al, 2005) and the exact data were not obtained, clinical significance and effect sizes were not calculated due to the possibility of inaccuracy.

3. RESULTS

3.1 Studies reporting on quality of life

Seven studies (Aguiar et al, 2007; Bergman et al, 2005; Kok et al, 2006; Minnee et al, unpublished; Smith et al, 2004; Virzi et al, 2007; Walton-Moss et al 2007) measured quality of life using the SF-36 (Ware et al, 1994). The SF-36 assesses 4 components of mental health: (1) energy and fatigue (vitality domain) (2) limitations on social functioning because of physical or emotional problems (social functioning domain); (3) limitations on usual activities because of emotional problems (role-emotional domain) and (4) psychological distress and well-being (mental health domain). Each of the dimension scores are expressed as a value between 0 and 100, with greater scores representing better health. The results can be represented in terms of the four domains or as an overall representation of general mental health in the Mental Health Component Summary Scale (MCS).

Results for the studies measuring postoperative quality of life using the SF-36 are presented in Tables 3 to 7. With the exception of Bergman et al (2005), the results presented represent the mean scores and standard deviations. Bergman et al (2005) reported the MCS as a mean

and standard deviation but the four corresponding domains as medians and interquartile ranges (IQR).

Bergman et al (2005) compared living kidney donors preoperative health related quality of life with their health related quality of life one month after donation (median follow-up period 29 days, IQR 22-30 days). The results suggested a non-significant improvement in overall psychological wellbeing following donation, as measured by the MCS (table 3). With respect to the individual SF-36 domains, Bergman et al (2005) reported a significant decline in the domains of vitality and social functioning one month post-transplant and a non-significant increase in the domain of mental health (tables 4, 5 and 7 respectively). This paper benefits from having a reference group, SF-36 scores for adults aged 35-44 years living in Montreal, which allows the reader to note that, preoperatively, donors scores on the vitality and social functioning domains were above that of the reference group, but, following donation fell below the scores for the reference group; donors postoperative scores vs. reference group scores[3]: vitality 60 (40-85) vs. 65 (50-75); social functioning 87.5 (62.5-100) vs. 100 (75-100). This paper is limited by the author only reporting changes in the SF-36 scores for the group as a whole and not reporting on how many donors had a significant improvement or decline in any of the SF-36 domains following donation. The author did note however, that one donor experienced a major depressive episode in the weeks following donation. As the results were reported as medians and not means, this donor's lower post-operative mental health domain score cannot account for the post-operative increase in the

[3] Results presented as median (Interquartile range)

mental health domain score failing to reach statistical significance for the group as a whole. However it does highlight that individual responses to living kidney donation vary and that reporting psychosocial outcomes of living kidney donation at an individual donor level will assist in understanding the impact of donation for the majority and facilitate identification of the risk factors for poor psychosocial outcome.

Smith et al (2004) compared pre-operative health related quality of life with health related quality of life at four- and twelve-months post-transplant. The authors found that donation was associated with a significant reduction in overall mental health, as measured by the MCS, with a moderate effect size four- and 12-months posttransplant (table 3). This paper benefits from having a reference group, SF-36 scores for adults from the State of Victoria, and thus allows the reader to note that, pre-donation, donors MCS scores were significantly higher than the population norm scores; donors mean preoperative MCS score vs. population norm MCS score: 54.7, sd 6.0 vs. 50.1, sd 9.0; t=3.23, df=4.960, P=0.001). However at four - and twelve months this difference was no longer statistically significant. It is important to note that this result was obtained when the author compared the pre-operative and post-operative scores for the group as a whole. A strength of this paper is that the author analysed the difference in pre- and post-operative SF-36 scores for each individual and in doing so found that for only 19% of the sample was the decrease in the MCS scores at 12-months large and clinically and socially relevant. Whereas for 10% of the sample there was an improvement in psychosocial functioning that was better than would be expected for the group. With respect to the individual SF-36 domain scores, Smith et al (2004) found that all post-operative domain scores were lower than preoperative scores one year post-transplant (tables 4-7). It is important to note that although only vitality reached statistical significance (table 4), both social functioning and role emotion were clinically and socially relevant with a moderate and

large effect size respectively (table 5 and 6 respectively). The results of this study differ from that of the other studies in that Smith et al (2004) found that the adverse affects of living kidney donation can last up to one year for some donors. By comparison, the majority of studies, discussed hereafter, indicate that post-operative SF-36 scores begin to return to baseline scores between three and six months postoperative, indicating the start of recovery. The difference in the results reported by Smith et al (2004) may be attributed to differences in the methodology. Pre-operative health related quality of life was assessed by an interview with a psychiatrist and a review of medical records in addition to the SF-36 questionnaire completed by the participant. Thus the preoperative assessment in this study is potentially more reliable as donors are more likely to underreport mental health concerns in a self report assessment due to concerns that doing so may prevent them from donating. Furthermore, the majority of the participants (n=85%) in this study underwent open donor nephrectomy, whereby the kidney is removed through an large open incision, this type of surgery is associated with a higher rate of complications, prolonged postoperative pain, and a slower recovery pace (Antcliffe et al, 2009; Bergman et al, 2005; Minnee et al, 2008a; Nanidis et al, 2008). By comparison, all of the participants in Bergman et al (2005) and Walton- Moss et al (2007) and 55% of the participants in Kok et al (2006) underwent laparoscopic donor nephrectomy, which involves removal of the kidney through a small incision using laparoscopic techniques. This type of surgery is associated with better psychosocial outcomes (Nanidis et al, 2008). Finally, over half (52%) of the participants in Smith et al (2004) were caregiver to the recipient, therefore in this study donors may have taken longer to recover because they were unable to fully rest due to having to care for the recipient or having reduced practical support from other family members who may have been caring for the recipient. The fact that the majority were caring for the recipient following surgery may also

explain the reduction in usual activities (role-emotion) and social functioning (social functioning domain).

Contrary to the results of Smith et al (2004), several studies have reported post-operative recovery between three and six months. Aguiar et al (2007) compared health related quality of life preoperatively with health related quality of life one- and three- months following donation. The authors aimed to compare the outcome of live kidney donation as a consequence of surgical access, either lombotomy incision (incision made below the ribs) or subcostal incision (incision made in front the eleventh rib) however to the papers benefit, the authors analysed inner group comparison as well as inter group comparison. The study also benefits from a random allocation of participants to surgical access and a blind assessment of outcome. Furthermore, the paper controlled for several confounding factors; the same surgeon performed the nephrectomy, the same anesthetic procedures were given to each donor and all donors were biologically related to the recipient. The results indicated that there was a significant decrease in all the SF-36 domain scores one month following surgery, however, this was partially recovered by three months posttransplant when scores were close to baseline (tables 4 to 7). Unfortunately the authors compared only the pre-operative and post-operative mean for the group and did not report on the difference at an individual donor level. As Smith et al (2004) has shown the impact of donation differs significantly between each individual donor with some donors having poor psychosocial outcome whilst others show improvement in their SF-36 scores. Similar results were found by Kok et al (2006); all SF-36 domain scores were significantly lower one month post transplant but showed the start of recovery at three months post transplant (tables 5 to 7) . The exception being vitality which remained significantly lower three months posttransplant but had returned to pretransplant levels by six months posttransplant (table 4). However, the result of Kok et al (2006) are

limited by the preoperative data being gathered the evening before surgery and therefore not reflecting premorbid functioning but potentially reflecting increased psychological distress due to impeding surgery. Walton-Moss et al (2007) also found that at three months post transplant all SF-36 domains scores were lower and that recovery began at six months posttransplant, however scores remained lower than baseline and with the exception of mental health were moderate clinically and socially relevant is possible that the preoperative assessment gathered in this study is more reliable and reflective of premorbid functioning as the preoperative data was gathered during the initial evaluation at the outpatient clinic. The results of Minnee et al (unpublished) concur but only for older donors[4]; vitality, social functioning and role emotion decreased three month post transplant and remained lower at six months post transplant with moderate to large effect sizes (tables 4, 5 and 6 respectively). With respect to younger donors however six months post transplant, social functioning, role emotion and mental health domain scores surpass pretransplant scores (tables 5, 6 and 7 respectively) and vitality was only slightly reduced (table 4). Unfortunately the results of this study are limited by the author not defining when the preoperative data was gathered and therefore the reader is left unsure of whether the preoperative SF-36 scores are representative of premorbid functioning. Virzi et al (2007) support this finding; the pre-operative scores on

[4] Minnee et al (unpublished) analysed older (≥55 years) and younger donors separately as the purpose of this study was to examine surgical outcome and quality of life in older live kidney donors.

the domains of social functioning and mental health were higher than baseline (tables 5 and 7 respectively) and the domain of vitality was only marginally decreased (table 4). This study does not have the limitation of Kok et al (2006) and Minnee et al (unpublished) as the preoperative data was gathered one month before donation. However as 67% (n=32) of the donors were donating to their child it is possible that improvement in SF-36 domain scores do not reflect the positive effects of donation but rather reduced psychological distress in parents as a consequence of improved health and successful transplantation in their children.

There are six other studies measuring quality of life following kidney donation which used a variety of measurements (table 8). Varma et al (1992) administered the Dysfunctional Analysis Questionnaire in which a score of forty is indicative of functioning at the pretransplant level. The results suggested only mild, non-significant dysfunction in social (42.3), vocational (44.3) and personal (42.5) functioning and premorbid levels for familial (39.2) and cognitive (40.5) functioning. Lumsdaine et al (2005) administered the WHO Quality of Life Questionnaire six weeks and twelve months posttransplant and reported that although donors psychological domain scores marginally decreased posttransplant, the scores remained significantly higher than UK norms (UK population norms: median 14.6, IQR 12.0-7.5; $p<0.001$). However the retention rate in this study was low (77%) and the author did not report on the status of those who dropped out of the study despite the author being part of the renal team and having access to this information from clinic appointments. Consequently the reader is unable to determine if those who dropped out of the study did so because they were having difficulty functioning whereas those who remained in the study represent donors with better psychosocial outcomes.

Simmons et al (1977) reported that the majority of donors (53%) had increased self esteem and happiness one year after successful donation. It has been suggested that this result was obtained because only donors involved in a successful transplantation were included in the analysis and as the donors were closely related to the recipient any increase in wellbeing is consequential to removal of kidney disease in their family member and removal of the impending fear of the operation. However the author argues that when compared with other control groups such as population norms and family member who decided not to donate, pretransplant the donors scores are equivalent but posttransplant considerably higher. These results were corroborated by Simmons et al (1982) who found that 51% of donors had higher scores on the Rosenberg self esteem questionnaire posttransplant.

3.2 Prevalence of psychiatric morbidity pre- and post- transplant

The MCS score is useful in screening for psychiatric disorders (Ware et al, 1994). For example, using a cut-off score of 42, the MCS has a sensitivity of 74% and a specificity of 81% in detecting patients diagnosed with depressive disorder (Ware et al, 1994). The results of Smith et al (2004) and Bergman et al (2005) show that although postoperative MCS scores fell below preoperative scores, the average score did not suggest that donors met caseness for major depressive disorder. Similarly, Varma et al (1992), Virzi et al (2007) and Yoo et al (1996) reported that scores on psychometric assessments used to measures depressive symptoms scores did not increase significantly following donation (Table 9).

With respect to prevalence, whilst Virzi et al (2007) reported a reduction in prevalence of depression, Minz et al (2005), Smith et al (2004) and Taghavi et al (2001) reported an increase (Table 9). The prevalence of depression may increase following donation due to reduction in activity, disruption of family life and daily routine and concerns about the loss of

an organ. Depression may also be associated with the experience of pain or illness. Providing information on the correlation between MCS and Physical Component Summary Scores on the SF-36 would provide insight in this area. Unfortunately only Smith et al (2004) reports these data.

With respect to anxiety, anxiety scores did not increase significantly following transplant (Minz et al, 2005; Varma et al, 1992; Virzi et al, 2007; Table 9). The above results however have not been replicated. Yoo et al (1996) found that donors were significantly more anxious about dying after donation, which may explain why donors experienced significantly more somatisation following donation (Varma et al, 1992). Similarly, Taghavi et al (2001) and Smith et al (2004) found that the prevalence of anxiety increased following donation. Smith et al (2004) reported a striking increase in the point prevalence (2%-15%) and the 12month prevalence (10-31%) of psychiatric caseness between the preoperative period and the 12 month postoperative period indicative of high incidence. The preoperative point prevalence for any of the disorders assessed for the donors was lower than that for the Australian population (2% vs. 11%) but the 12 month point prevalence was higher (15%). Specifically for anxiety and depression the 12 month point prevalence for the Australian population was 12% which is lower than the 12 month point prevalence for the donors (18%)

3.3 Factors that influence psychosocial outcome of live kidney donors

Understanding the factors that lead to poorer psychosocial outcome after donation for some individuals will inform the psychological screening of potential donors and post-operative follow-up of donors. The factors that increase the risk of poor psychosocial outcome reported in the included studies are discussed below.

The growing need for less invasive or less painful nephrectomy have led to a variety of surgical accesses to approach the kidney being developed. The introduction of laparoscopic donor nephrectomy (LDN) aims to replace the traditional open door nephrectomy (ODN) which is associated with a higher rate of complications, longer hospital stays, prolonged postoperative pain, cosmetic consequences and slower recovery pace (Antcliffe et al, 2009; Bergman et al, 2005; Minnee et al, 2008a; Nanidis et al, 2008). Only Kok et al (2006) investigated the impact of surgical technique on health related quality of life. The results indicated that donors who underwent mini-incision donor nephrectomy (MIDN) did not have poorer outcomes than those that underwent LDN, with the exception that for individuals undergoing LDN, role emotion was not significantly affected by donation (table 6). This paper has several limitations. Firstly, donors whose LDN was converted to an MIDN due to complications were still analysed in the LDN group. Secondly, the MIDN group had more female participants than the LDN group and females in the Dutch population are reported to have significantly lower SF-36 domain scores (Aaronson et al, 1998). Therefore as a consequence of the gender distribution one would expect scores for the MIDN group to be lower. These results are also surprising as Minz et al (2005) found that prolonged hospitalisation and persistent pain was associated with poorer psychosocial outcomes for donors and that postoperative depression was higher in those who believed that donation had a negative impact on their health ($p<0.0001$).

Yoo et al (1996) found that non-related live kidney donors reported significantly more life satisfaction and psychological well-being after donation than those who were related donors ($p<0.05$). This may be because related donors are carers for the recipients and therefore have less time in pleasurable activities or less time to recuperate. However, Smith et al (2004) found that the relationship between the donor and recipient (carer or not) did not impact on

the MCS scores at 12months. Therefore this may be explained by related donors being more affected by recipient reciprocity; Minz et al (2005) found that poor recipient reciprocity was associated with poor psychosocial outcome whilst Varma et al (1992) believed that the significant increase in somatisation following donation was the result of lack of attention paid to the donors after donation.

The result of Smith et al (2004) suggest that current and past psychiatric symptoms are an indicator of psychosocial outcome following donation; donors preoperative Transplant Evaluation Rating Scale (TERS) score significantly correlated with MCS at 4-months postoperative ($r=0.42$, $P=0.003$) and 12- months ($r=-0.28$, $P=0.049$) postoperatively. TERS scores are a measure of past and present psychiatric symptoms and personality and of compliance, coping behaviour and social support. It is not surprising therefore that the American Society of Transplantation recommends that a formal psychosocial evaluation be given to donors before they are approved for donation.

4. SUMMARY OF LIMITATIONS AND IMPLICATIONS FOR FUTURE RESEARCH

Living kidney donors are a select sample of healthy individuals and as such pretransplant their scores on measurement of quality of life will be higher than that obtained from population norms (Walton-Moss et al, 2007). Therefore, in order to give an accurate description of the psychosocial outcomes of live kidney donation it is essential to use a prospective study design in which quality of life is assessed pre- and posttransplant. However it may be argued that this methodology introduces confounding factors and limitations to interpreting results. For example, where psychological distress is not significantly greater after transplant one could argue that pretransplant donors are distressed despite not

encountering any stressful event at that time. This is possibly due to continuous concerns regarding their impending operation and subsequent recovery and in some, concerns about the health of the recipient. However posttransplant this anxiety abates, at least in those where there has been a successful transplant. Support for this hypothesis being that following donation trait anxiety scores significantly decreased possibly indicating that the experience of donation had lowered the individual's propensity to interpret situations as threatening and experience anxiety (Minz et al, 2005). This may also explain why some studies find that donation results in increased happiness and decreased levels of distress, perhaps because the donors' distress may be relieved due to improved health of the recipient and that fact that surgery is behind them. The only way to fully explore this area would be to compare post transplant functioning with donors' premorbid functioning, before the onset of kidney disease in the recipient or at least before the donor consented to donate. However as this would not be feasible it may be possible to further consider this confounding factors by including control subjects such as family members who are suitable for donation but chose not to donate.

With the exception of Smith et al (2004), psychological well-being was assessed using a self-report measure. It is possible that pretransplant donors underreport psychological problems and difficulties in functioning due to the desire to become a donor. Whereas following transplantation the donors do not have to meet an inclusion criterion and therefore donors provide more reliable reports. This hypotheses may be supported by the results of Smith et al (2004); in this study, current and past (last 12 months and lifetime) psychiatric caseness was established by a psychiatrist using information from a semi structured interview and medical records combined with information from the self- completed patient health questionnaire. Furthermore donors and their families in this study were given an education session stressing

the importance of mental wellbeing and the implication of hiding symptomatology and were informed that the psychiatrist had access to medical records and interviews conducted over the preceding months. The results of this study in comparison to others indicates that live kidney donation has a negative impact on the quality of life for some donors which can last up to 12-months post transplant. Furthermore, unlike others, this study reported a striking increase in point prevalence and incidence post transplant. Unfortunately Smith et al (2004) did not report the accuracy of the self completed assessment in comparison to the review of medical records and assessment by the psychiatrist.

Another limitation of the literature involves selection bias. It is possible that donors with adverse outcomes are less willing or able to participate. Bergman et al (2005) noted that although donors who withdrew from the study postoperatively did not differ with respect to demographic and intraoperative data, they did have a lower postoperative quality of life. This is an area that warrants further investigation. Unfortunately no other study reported on the outcome of those refused to participate in the study or were lost to follow up despite this possibly being obtainable from medical record or follow up clinic reports.

7. CONCLUSIONS

The literature reviewed suggests that live kidney donation causes short term changes in quality of life. However, for the majority of donors, postoperative quality of life does not differ significantly from preoperative quality of life and the changes are not clinically or socially relevant. Despite this, however, as donors are undergoing an unnecessary invasive procedure for the benefit of another, it is imperative in order to prepare for the posttransplant period that donors are aware of the psychosocial outcomes of live kidney donation.

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Table 1: Quality rating for included articles.

	Aguiar et al (2007)	Bergman et al (2005)	Kok et al (2006)	Lumsdaine et al (2005)	Minz et al (2005)
The study addresses an appropriate and clearly focused question.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The main objective of the study is clearly defined	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Selection of Subjects					
The sample is representative of the population being studied.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study reports the sample size.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study indicates how many of the people asked to take part did so	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	No 0/1
The study reports the retention rate for each stage of follow up	Yes 1/1	Yes 1/1	No 0/1	No 0/1	Yes 1/1
Comparison is made between full participants and those lost to follow up.	Yes 1/1	Yes 1/1	No 0/1	No 0/1	No 0/1
The study states the inclusion and exclusion criteria.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	No 0/1
Assessment					
The outcomes are clearly defined.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The measure of assessment of outcome is stated and is reliable and valid	Well covered 2/2	Well covered 2/2	Well covered 2/2	Well covered 2/2	Adequately covered 1/2
Confounding Variables					
The main potential confounders are identified and taken into account in the design and analysis.	Well covered 2/2	Adequately covered 1/2	Well covered 2/2	Well covered 2/2	No, poorly addressed 0/2
Statistical analysis					
The statistical analysis is appropriate given the study design and the outcome measures used	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Are effect sizes, confidence interval and p-values been reported where appropriate reported	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1

	Simmons et al (1977)	Simmons et al (1982)	Smith et al (2004)	Taghavi et al (2001)
The study addresses an appropriate and clearly focused question.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The main objective of the study is clearly defined	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Selection of Subjects				
The sample is representative of the population being studied.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study reports the sample size.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study indicates how many of the people asked to take part did so	No 0/1	Yes 1/1	Yes 1/1	No 0/1
The study reports the retention rate for each stage of follow up	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Comparison is made between full participants and those lost to follow up.	No 0/1	No 0/1	Yes 1/1	No 0/1
The study states the inclusion and exclusion criteria.	Yes 1/1	Yes 1/1	No 0/1	No 0/1
Assessment				
The outcomes are clearly defined.	No 0/1	Yes 1/1	Yes 1/1	Yes 1/1
The measure of assessment of outcome is stated and is reliable and valid	No, poorly addressed 0/2	Adequately addressed 1/2	Well covered 2/2	Well covered 2/2
Confounding Variables				
The main potential confounders are identified and taken into account in the design and analysis.	No, poorly addressed 0/2	No, poorly addressed 0/2	Well covered 2/2	Adequately covered 1/2
Statistical analysis				
The statistical analysis is appropriate given the study design and the outcome measures used	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Are effect sizes, confidence interval and p-values been reported where appropriate reported	Yes 1/1	Yes 1/1	Yes 1/1	No 0/1

	Varma et al (1992)	Virzi et al (2007)	Walton-Moss et al (2007)	Yoo et al (1996)
The study addresses an appropriate and clearly focused question.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The main objective of the study is clearly defined	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Selection of Subjects				
The sample is representative of the population being studied.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study reports the sample size.	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
The study indicates how many of the people asked to take part did so	No 0/1	No 0/1	Yes 1/1	No 0/1
The study reports the retention rate for each stage of follow up	No 0/1	No 0/1	Yes 1/1	No 0/1
Comparison is made between full participants and those lost to follow up.	No 0/1	No 0/1	No 0/1	No 0/1
The study states the inclusion and exclusion criteria.	No 0/1	No 0/1	No 0/1	No 0/1
Assessment				
The outcomes are clearly defined.	Yes 1/1	Yes 1/1	Yes 1/1	No 0/1
The measure of assessment of outcome is stated and is reliable and valid	Well covered 2/2	Well covered 2/2	Well covered 2/2	Well covered 2/2
Confounding Variables				
The main potential confounders are identified and taken into account in the design and analysis.	Well covered 2/2	No, poorly addressed 0/2	Well covered 2/2	No, poorly addressed 0/2
Statistical analysis				
The statistical analysis is appropriate given the study design and the outcome measures used	Yes 1/1	Yes 1/1	Yes 1/1	Yes 1/1
Are effect sizes, confidence interval and p-values been reported where appropriate reported	Yes 1/1	Yes 1/1	No 0/1	Yes 1/1

Table 2: Characteristics of included studies

Study	Quality rating	Type of nephrectomy	No. included in analysis reported	Demographics Gender (%M:F) Mean age (sd/range)	Follow-up period	Assessment: variable assessed
Aguiar et al (2007)	Moderate	ODN	N= 60 Lombotomy access: 30 Subcostal access: 30	32:68 41.6 (8.9)	1 & 3 months	SF-36: QoL
Bergman et al (2005)	Good	LDN	35	43:57 40 (31-49)	1 month	SF-36: QoL Self –rated recovery
Kok et al (2006)	Good	ODN LDN	N= 100 ODN :45 LDN: 55	ODN 24:76 51 (22-90) LDN 51:49 53 (20-74)	1, 3 6 & 12 months	SF-36: QoL VAS: perceived health status
Lumsdaine et al (2005)	Good	ODN	40	38:62 49 (24-71)	6 weeks & 12 months	WHOQOL: QoL
Minnee et al (unpublished)	N/A	-	-	-	1& 3 months	SF 36: QoL
Minz et al (2005)	Moderate	NR	75	28:72 42 (11.6)	3 months	Modified BDI Spielbergers' state and trait anxiety questionnaire Purpose made questionnaire measuring donors' perception of physical and emotional recovery from surgery.
Simmons et al (1977)	Moderate	NR	128	NR	5 days (n=128) 1 year (n=111)	Purpose made happiness and self-esteem scales constructed from validated questionnaires.

Study	Quality rating	Type of nephrectomy	No. included in analysis reported	**Demographics** Gender (%M:F) Mean age (sd/range)	**Follow-up period**	**Assessment: variable assessed**
Simmons et al (1982)	Moderate	NR	135	NR	3 weeks, 1 & 5-9 years	Rosenberg Self Esteem Scale
Smith et al (2004)	Good	ODN LDN	N= 48 ODN: 41 LDN: 7	46:54 48.7 (11.9)	4 & 12 months	PHQ: psychiatric diagnosis SF-36: QoL
Taghavi et al (2001)	Moderate	NR	40	72:28 22 (18-40)	1 &3 months	SCL-90: psychiatric diagnosis
Varma et al (1992)	Good	NR	31	68:32 46.2 (15.7)	1 week	PEN inventory: personality MHQ: psychological distress DAQ: psychological functioning
Virzi et al (2007)	Moderate	ODN	48	21:79 54.2 (33-81)	6 months	MMSE: psychiatric diagnosis HADS: depression and anxiety Self rated anxiety SF-36: QoL
Walton-Moss et al (2007)	Moderate	LDN	15	33:67 46 (11.8)	3&6months	SF-36: QoL
Yoo et al (1996)	Poor	NR	25	NR	1 month	BDI: depression Hostility scale Death Anxiety scale Campbells' Index of wellbeing: QoL

ODN: open live donor nephrectomy LDN: laparoscopic live donor nephrectomy NR: not reported MMSE: mini mental state exam
QoL: quality of life WHOQOL: world health organisation quality of life questionnaire. VAS: visual analogue scale
PHQ: patient health questionnaire PRS: post operative recovery scale. DAQ: dysfunctional analysis questionnaire
MHQ: Middlesex Hospital Questionnaire

Table 3: SF-36 Mental Health Component Summary Score

Study	Preoperative	Postoperative period (months)			p-value	Effect size
		1	4	12		
Smith et al (2004)	54.7 (6.0)		50.9 (8.6)	51.5 (9.1)	4 months: 0.002 12 months: 0.02	4 months: -0.63 12 months: -0.53
Bergman et al (2005)	53.3 (9.2)	54.6 (8.8)			0.2	0.14

All results reported are means (standard deviation)

Table 4: SF-36 Vitality domain score.

Study	Preoperative	Postoperative period (months)				p-value	Effect size	Clinically significant
		1	3	6	12			
Aguiar et al (2007)	**Lombotomy incision** 87.0 (12.1)	77.8 (19.9)	85.8 (12.8)	-	-	0.002	1 month: -0.8 3months: -0.1	1 month: min. 3 months: no
	Subcostal incision 82.7 (13.8)	75.0 (17.5)	85.3 (13.9)	-	-	0.002	1 month:-0.6 3months: 0.19	1 month: min 3 months: no
Minnee et al (unpublished)	**Younger donors** 83.6 (16.5)		78.1 (20.4)	82.6 (17.9)			3months:-0.3 6months:-0.06	3months:min. 6months:no
	Older donors (≥55 years) 87.9 (13.8)		78.1(19.5)	80.3 (20.3)			3 months: -0.7 6 months: -0.55	3 months: min 6months: min
Smith et al (2004)	77.6 (12.6)	-	-		68.9 (19.4)	0.001	-0.69	Min
Walton-Moss et al (2007)	73.9		42.1	58.2		NR	-	3 months: mod. 6 months: mod
Bergman et al (2005)*	80 (65-85)	60 (40-85)				0.003		
Virzi et al (2007)	56.7 (14.8)			55.7 (16.6)		0.7	-0.07	No
KOK ET AL (2006)[1]	**ODN** 80	63	72	70	80	1 month: 0.02 3 months: 0.02	-	-
	LDN 78	60	74	71	76	1 month: <0.002 3months: 0.04		

ODN denotes open donor nephrectomy LDN denotes laparoscopic donor nephrectomy *results presented as median (IQR) all other results reported are means (standard deviation)

Table 5: SF-36 Social functioning domain score.

Study	Preoperative	Postoperative period (months)				p-value	ES	Clinically significant
		1	3	6	12			
Aguiar et al (2007)	**Lombotomy incision** 95.0(10.2)	75.4 (24.5)	82.5(13.5)			<0.001	1month:-1.92 3months:-1.2	1month: mod 3months: mod.
	Subcostal incision 91.7 (17.5)	81.7 (118.5)	84.8 (9.1)			<0.001	1month:-0.57 3months:-0.4	1month: mod. 3months: min
Smith et al (2004)	95.4(9.5)				89.9 (21.2)	NS	-0.58	Min.
Walton-Moss et al (2007)	99.1		66.1	80.4		NR	NR	3 months: mod. 6 months: mod.
Bergman et al (2005)	100 (87.5-100)	87.5 (62.5-100)				0.03		
Virzi et al (2007)	52.7 (12.7)			57.7 (10.8)		0.06	0.39	Min.
Minnee et al (unpublished)	**Younger donors** 89.6 (18.3)		91.6 (15.9)	95.3 (12.3)			3 month: 0.1 6 month: 0.3	3months: no 6 months: min.
	Older donors (≥55years) 96.1 (8.3)		87.5 (23)	86 (22.4)			3 month: -1.03 6 month: -1.2	3months: min. 6 months: mod.
Kok et al (2006)	ODN 90	70	85	90	90	1 month: <0.05 3months: NS	-	-
	LDN 92	75	90	90	95	1 month: :0.002 3months: NS	-	-

ODN denotes open donor nephrectomy LDN denotes laparoscopic donor nephrectomy *results presented as median (IQR) all other results reported are means (standard deviation)

Table 6: SF-36 Role Emotion domain score

Study	Preoperative	Postoperative period (months)				p-value	Effect Size	Clinically significant
		1	3	6	12			
Aguiar et al (2007)	**Lombotomy access** 96.7 (10.2)	86.8 (20.4)	87.5 (16.2)			0.015	1month:-0.97 3months:-0.9	1month:min 3months:min
	Subcostal access 94.4 (15.4)	90 (19.9)	85.7 (16.9)			0.015	1month:-0.29 3months:-0.56	1month:min. 3months:min
Smith et al (2004)	98.6 (6.7)				93.1 (22.87)	NS	-0.82	Min.
Walton-Moss et al (2007)	97.5		71.8	79.5		NR	NR-	3 months: mod 6 months: mod.
Bergman et al (2005)*	100 (100-100)	100 (66.7-100)				0.007		
Minnee et al (unpublished)	**Younger donors** 91.4 (23)		88.5 (29.4)	92.8 (22.4)			3 month: 0.13 6 month: 0.06	3 month: no 6 month: no
	Older donors (≥55 years) 97.6 (8.7)		81 (35.9)	82.7 (37.4)			3 month: 1.9 6 month: 1.7	3 month: mod. 6 month: mod.
Kok et al (2006)	**ODN** 92	85	90	93	98	1 month: <0.05 3months: NS	-	-
	LDN 90	65	92	95	95	1 month:≤0.002 3months: NS		

ODN denotes open donor nephrectomy LDN denotes laparoscopic donor nephrectomy *results presented as median (IQR) all other results reported are means (standard deviation)

Table 7: SF-36 Mental Health domain score

Study	Preoperative	Postoperative period (months)				p-value	Effect Size	Clinically significant
		1	3	6	12			
Aguiar et al (2007)	**Lombotomy access** 85.2 (13.7)	81.5(20.1)	91.0 (15.1)			0.035	1month:-0.27 3 months:0.4	1 month: no 3 months: min
	Subcostal access 84.5 (12.4)	79.1(20.1)	86.4 (16.7)			0.035	1month:-0.4 3 months: 0.15	1 month: min 3 months: no
Smith et al (2004)	82.6 (13.5)				78.4 (16.1)	NS	-0.31	No
Walton-Moss et al (2007)*	85.1		75.7	76.6		NR	NR	3 months: min 6 months: min
Bergman et al(2005)	84 (72-88)	88 (76-96)				0.09		no
Virzi et al (2007)	64.8 (13.4)			66.6 (17)		0.7	0.13	no
Minnee et al (unpublished)	**Younger donor** 86.1 (11.3)	90.9 (12.5)		90.9 (12.4)			3 month: 0.4 6 month: 0.4	3 month: no 6 month: no
	Older donor (≥55 years) 88 (14.2)		90 (14.7)	86.5 (20)			3 month: 0.14 6 month: -0.1	3 month: no 6 month: no
Kok et al (2006)	**ODN** 70	65	65	73	68	1 month: <0.05 3months: NS	-	-
	LDN 68	62	63	65	65	1 month:<0.002 3months: NS		

ODN denotes open donor nephrectomy LDN denotes laparoscopic donor nephrectomy *results presented as median (IQR) all other results reported are means (standard deviation)

Table 8: Quality of life following live kidney donation

Study	Instrument	Preoperatively	Postoperatively	Effect size/p-value
Lumsdaine et al (2005)	WHOQoL	**Psychological** 16.7 (16.0-8.0)	6 weeks:16.0 (14.7-6.7) 12months: 16.0 (14.0-7.2)	
		Social 17.3 (9.3-0)	6 weeks: 17.3 (10.6-0.0) 12months: 17.3 (6.7-0.0)	
		Environmental 17.0 (12-0)	6 weeks: 16.5 (9.00-0.0) 12months: 16.0 (11.0-0.0)	
Minz et al (2005)*	Perceived Social Support Questionnaire	58 (54-62)	3months: 60 (58-64)	p=0.000.
Yoo et al (1996)	Campbell's index of wellbeing	39.23	39.43	p=-0.06

* results presented as median (IQR), all other results presented as mean (sd)

Table 9: Prevalence of psychological symptoms in live kidney donors.

Study	Instrument	Preoperative period	Postoperative period	Results
Varma (1992)	Middlesex Hospital Questionnaire	Free floating anxiety: 1.68 obsession:2.74 phobic anxiety:1.83 somatic anxiety:1.61 depression traits:2.58 hysteria traits:1.32	Free floating anxiety: 1.9 obsession: 3.55 phobic anxiety:2.06 somatic anxiety:3.23 depression traits:2.32 hysteria traits:1.45	The preop. scores were within normal range and this did not change postop. with the exception of somatisation which increased significantly ($p<0.001$).
	PEN inventory	Psychoticism:2.26 Extraversion:10.45 Neuroticism:3.10 L:10.03	Psychoticism:1.94 Extraversion:10.32 Neuroticism:3.97 L:9.52	Preop. scores were within normal range indicating emotional stability. Postop. Scores were not significantly different in any donors
Minz et al (2005)*	Modified BDI	Mean score: 0 (0-1) Prevalence of mild depression: 0 Prevalence of major depression: 0	Mean score: 0 (0-2) Prevalence of mild depression: 4 Prevalence of major depression: 0	Statistically significant increase in scores of the modified BDI ($p=0.046$). Increase in BDI score due to new cases of depression alone.
	Spielberger State and Trait anxiety questionnaire	Anxiety Trait:32 (28-36) Anxiety State: 31 (26-34)	Anxiety Trait: 27 (24-31) Anxiety State: 24 (22-30)	Anxiety trait scores were significantly lower postop. ($p=0.001$) but remained within the normal range (25-42) Anxiety state scores were significantly lower postop. ($p<0.001$) and postoperatively were not within the normal range (31-43)
Yoo et al (1996)	BDI	Mean: 7.8	Mean: 7.83	No significant difference in mean BDI scores
	Hostility scale from SCL-90-R	8.14	9.97	Statistically significant increase ($p<0.05$)
	Death anxiety	20.38	23.00	Statistically significant increase in anxiety concerning dying
Virzi et al (2007)	Hamilton Rating Scale for Depression	5.8 (3.4) Score>7: 37.5%	6.5 (5.3) Score>7: 33.3%	Non significant ($p=0.4$) increase in scores
	Hamilton Anxiety Scale	8.9 (5.5) Score>18: 12.6%	8.9 (5.7) Score>18: 0%	Non significant ($p=0.9$) increase in scores
	Self-Rating Anxiety Scale	28.2 (5.2)	28 (5.1)	Non significant in scores ($p=0.8$)

* results presented as median (IQR), all other results presented as mean (sd)

Study	Instrument	Preoperative period	Postoperative period	Results
Smith et al (2004)	DSM-IV criteria assessed using data from patient health questionnaire, clinical interview and casenote review.	Cases: 1;Depressive disorder, dysthymia Point prevalence: 2%	**4 months** Cases: 12; adjustment disorder (8); anxiety disorder (3); depressive disorder dysthymia (1) Point prevalence: 25% Incidence: 23% **12 months** Cases:7; adjustment disorder (1); anxiety disorder (1); depressive disorder (5, major depression n=3, dysthymia n=2) Point prevalence: 15% Incidence: 13%	12-month prevalence 31% postoperatively compared with 10% preoperatively. 12 month incidence of 29%. Five (71%) of the cases at 12 month postoperative were cases at 4month postoperative.
Taghavi et al (2001)	SCL-90	All scores within the normal range. No cases	Depression: 7 (5 codiagnosed) Anxiety: 6 (5 codiagnosed) Obsession: 9 (6 codiagnosed) Conversion: 1 Phobia: 0	Significant changes found in 13 cases. No difference between 1- and 3-month follow-up.

CHAPTER 2: MAJOR RESEARCH PROJECT

THE STUDY OF LIVING KIDNEY DONOR DECISION-MAKING AND PSYCHOSOCIAL OUTCOMES

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ABSTRACT

Background

Individuals with end-stage kidney disease need dialysis or a kidney transplant. Kidney transplantation from a living donor is the preferred treatment. Live kidney donor transplantation, however, is an invasive surgery performed on a healthy individual for the benefit of another person. Therefore, donors should be fully informed of the risks involved in donation. The medical outcomes for kidney donors are well known, however, the research investigating the psychosocial impact of donation is limited. Understanding the psychosocial outcome of living kidney donation would promote informed consent, allow donors to plan their postoperative recovery period, and guide the development of services that maintain the long-term health of donors.

Aims

This study aimed to investigate the postoperative quality of life of live kidney donors, to investigate which variables predict postoperative psychosocial outcome, with particular interest in the variable of coping style and to gather information regarding how individuals decide to become living kidney donors and how satisfied they are with their pre- and post-operative care.

Methods

Living kidney donors at Glasgow Western Infirmary, Manchester Royal Infirmary and St. James' Hospital, Leeds were asked to complete a preoperative assessment consisting of the SF-36, HADS, COPE and The Donor Decision Control Scale. Four weeks postoperative, donors were asked to again complete these questionnaires, and in addition The Living Donor Survey.

Results

Complete data was available for thirteen donors. The results indicate that live kidney donation had a significant adverse affect on the physical wellbeing of the donors; the postoperative scores on the PCS and all of the corresponding domains were significantly lower and with a large effect size. Five (38%) of the donors experienced postoperative complications, three of whom were readmitted to hospital. With respect to psychological wellbeing, donors' scores on the MCS did not differ significantly from their preoperative scores. With respect to anxiety, for the group as a whole, postoperative HADS anxiety scores were lower and the severity and prevalence of anxiety symptoms reduced. For depression there was only a marginal increase in HADS depression scores. Analysis of each individual's outcomes indicated that there was a marked difference in the impact of donation. The results suggest that poor psychosocial outcome following donation was marginally associated with relying on mental disengagement as a coping strategy. Improved outcome in the postoperative period was associated with seeking social support

Conclusions

The physical health of donors is adversely affected by live kidney donation. Four weeks postoperatively live kidney donors report their physical health as being worse than those with long-standing illness. The psychological wellbeing of the majority of donors appears to be largely unaffected by live kidney donation. However, a minority of donors report a poorer psychological wellbeing following donation. Individuals who use active coping strategies have higher postoperative MCS scores, reflecting better psychological wellbeing. However, this conclusion should be interpreted with caution due the small sample size and therefore the possibility of a type I error.

1. INTRODUCTION

End-stage kidney disease is the complete, or almost complete, failure of the kidneys to function. The kidneys can no longer remove waste, concentrate urine, and regulate many other important bodily functions. Patients who have reached this stage need dialysis or a kidney transplant. Kidney transplantation is preferred because of superior quality of life and survival rates. Live kidney donor transplantation provides a better outcome than a cadaveric donor[5] transplantation. One year graft survival rates for live kidney donor transplantation range from 88.8% to 93.9% in comparison to 75.7% - 87.7% for cadaveric donor transplantation. Graft lifespan is also superior for living donor transplantation; a living donor graft had a life span of on average 21.6 years in comparison to 13.8 years for a cadaveric donor graft (Hariharan et al, 2000).

The Human Tissue (Scotland) Act (2006) permitted donations from non-related donors and withdrew previous restrictions prohibiting individuals obtaining anything in return for donating and thus led to the introduction of new types of donor-recipient relationships (Table 1). As a consequence of this act and increased awareness of the benefits of live donation, the number of live kidney donor transplants in the UK has increased across the years; there were 475 live kidney donor transplants in 2004-05, 589 in 2005-06, 690 in 2006-07, 831 in 2007-08, 927 in

[5] cadaveric donor transplant is a kidney transplant from a deceased donor.

2008-09 and 1,038 in 2009-10. Consequently live kidney donor transplants represent more than one in three of all kidney transplants (NHS blood and Transplant statistics).

Insert Table 1 here

Live kidney donor transplantation, however, is an invasive surgery performed on a healthy individual for the benefit of another person. Therefore, donors should be fully informed of the risks involved in donation. Furthermore, the effect of donation on the donor must be assessed to ensure that donation does not diminish the long-term psychological or physical health of the donor. Consequently, The Institute of Medicine and several transplant organisations including the American Society of Transplant Surgeons, The Division of Transplantation of the Health Resources and Services Administration, and the National Institutes of Health have suggested that further research into this area is needed in order to guide informed consent (Adams et al, 2002). Donors have also requested more information concerning outcomes; ten out of twenty donors interviewed by Walton-Moss et al (2007) reported that it would be beneficial to have more information concerning the postoperative recovery period such as the pace of recovery and amount of pain to expect.

1.1 HEALTH RELATED QUALITY OF LIFE FOLLOWING LIVE KIDNEY DONATION

Physical health

The post-operative physical health of donors has been extensively investigated and it is now recognized that if a kidney is removed, the remaining kidney increases slightly in size and capacity and can carry on the function of the two. Kidney donors do not experience any long-

term medical complications following donation; the life expectancy of donors is similar to that of non-donors and the risk of end stage renal failure does not increase (Ibrahim et al, 2009). The potential of having complications associated with the donation process is also low; the risk of death and serious surgical complications are 0.005% and 0.3% respectively (Nolan et al, 2004). The length of time to recover from live kidney donation varies from 2 - 12 weeks (NHS blood and Transplant website). Recovery time will depend in part on whether the kidney is removed by an open incision (open donor nephrectomy), which involves a larger incision and therefore a longer recovery time estimated at eight weeks, or by laparoscopy (laparoscopic donor nephrectomy), which involves several small incisions and a shorter recovery time estimated at four weeks (NHS blood and Transplant website).

Psychosocial Outcomes

With respect to psychosocial outcomes, initially the available literature concluded that live kidney donors have a highly positive experience with kidney donation and an enhanced self-esteem and self-regard related to this act. This conclusion was drawn from several studies reporting that donors' post-operative psychosocial outcome scores on the Medical Outcome Study 36-item Short Form Health Survey (SF-36) (Ware et al, 1994) indicated a higher or comparable quality of life to aged matched controls (Buell et al, 2005; Chen et al, 2004; Fehrman- Ekholm et al, 2000; Giessing et al, 2004; Johnson et al, 1999; Perry et al, 2003). However, more recently it has been argued that living kidney donors are a select sample of healthy individuals and therefore pre-donation SF-36 scores are higher than general population scores (Walton-Moss et al, 2007). Thus it is possible that donation impacts negatively on donors' psychosocial health yet their scores on health-related quality of life questionnaires will

remain comparable with population norms. Therefore, in order to give an accurate description of the pace of recovery following donation and the psychosocial outcome of donation, a prospective study design is required.

Within the renal transplant literature, the SF-36 is the most frequently used patient-reported measure of quality of life (Butt et al, 2008). The SF-36 assesses 4 components of mental health: (1) energy and fatigue (vitality domain) (2) limitations on social functioning because of physical or emotional problems (social functioning domain); (3) limitations on usual activities because of emotional problems (role-emotional domain) and (4) psychological distress and well-being (mental health domain). The results of the SF-36 can be expressed as domain scores with a value between 0 and 100, with greater scores representing better health, or as an overall representation of general mental health in the Mental Health Component Summary Scale (MCS). Seven prospective studies have measured the psychosocial outcomes for live kidney donors using the SF-36 (Aguiar et al, 2007; Bergman et al, 2005; Kok et al, 2006; Minnee et al, unpublished, Smith et al, 2004; Virzi et al, 2007; Walton-Moss et al 2007). Minnee et al (unpublished) represents an unpublished dataset obtained from the authors which supersedes the data published in Minnee et al (2008a and b). A summary of these studies is discussed here and the full data for each of the studies are presented in Tables 3-7 in the systematic review chapter.

With respect to overall psychological wellbeing, the results from the MCS suggest that the majority of donors are not adversely affected by kidney donation. Bergman et al (2005) reported a non-significant improvement in the MCS score following donation; mean MCS score at baseline vs. mean MCS score 1-months postoperative: 53.3 (9.2) vs. 54.6 (8.8), p=0.2. Smith et

al (2004) found that donation was associated with a significant reduction in overall mental health with a moderate effect size four- and 12-months post-operative; mean MCS score at baseline vs. mean MCS score at 4-months and 12 months postoperative respectively: 54.7(6.0) vs. 50.9 (8.6), p=0.002 and 51.5(9.1), p=0.02. However, for only 19% of the sample was the decrease in the MCS scores at 12-months large and clinically and socially relevant, indicated by a change of ten or more points. Whereas, for 10% of the sample there was an improvement in psychosocial functioning that was better than would be expected for the group.

With respect to the individual SF-36 domains, Bergman et al (2005) showed a significant decline in the domains of vitality, social functioning and role emotion one month post-transplant (Tables 3, 4 and 5 respectively). Aguiar et al (2007) found that there was a significant decrease in all the SF-36 domain scores one month post-transplant, however this was partially recovered by three months posttransplant when scores were close to baseline (Tables 3 to 6). Similarly, Kok et al (2006) found that all SF-36 domain scores were significantly lower one month post-transplant but showed the start of recovery at three months post-transplant (Tables 3 to 6). Vitality, however, remained significantly lower three months post-transplant but had returned to pre-transplant levels by six months post-transplant. The results were similar for both open donor nephrectomy (ODN)[6] and laparoscopic donor nephrectomy (LDN)[6] with the exception being that

[6] LDN also referred to as key hole surgery involves removing the kidney through a smaller incision and performing the nephrectomy with the assistance of a telescopic lens. In comparison, ODN involves surgery completed manually and the incision is therefore larger.

for individuals undergoing LDN, role emotion was not significantly affected by donation. By comparison, Smith et al (2004) reported that one year post transplant, all SF-36 domain scores were lower than the preoperative scores, indicating that live kidney donation adversely affects quality of life for a longer period than reported by the aforementioned studies. The difference between the preoperative scores and the one year follow-up scores was statistically significant only for the domain of vitality (p=0.001). However, the difference between the preoperative scores and the one-year follow scores for both social functioning and role emotion were clinically and socially relevant with moderately and large effect sizes respectively. Walton-Moss et al (2007) also found that, at three months post-transplant, all SF-36 domains scores were lower and that recovery began at six months post-transplant. However, scores remained lower than baseline and, with the exception of mental health, were moderately clinically and socially relevant (Tables 2 to 6). The results of Minnee et al (unpublished)[7] concur but only for older donors; vitality, social functioning and role emotion decreased three month post transplant and remained lower at six months post transplant with moderate to large effect sizes (Tables 3, 4 and 5 respectively) . With respect to younger donors, however, six months post transplant, donors' social functioning, role emotion and mental health domains surpassed pre-transplant scores (Tables 4, 5 and 6 respectively) and vitality was only slightly reduced. Virzi et al (2007) also reported positive effects of kidney donation in all domains, the exception being vitality which showed a marginal decrease (Tables 2 to 6). Bergman et al (2005) showed a non-significant

[7] The author analysed older (≥ 55 years) and younger donors separately as the purpose of this study was to examine surgical outcome and the quality of life in older living donors.

(p=0.09) increase in the domain of mental health. Thus, in summary, for some individuals' donation impacts negatively on their psychosocial functioning, but only for between three and six months after which quality of life begins to return to pre-transplant levels.

The impact of kidney donation on the psychiatric morbidity of donors remains unclear. Virzi et al (2007) reported a non-significant reduction in depression and anxiety scores as measured by the Hospital Anxiety and Depression Scale (HADS); baseline HADS scores vs. HADS scores 6-month postoperative: anxiety 8.9 (5.5) vs.8.9 (5.7) p=0.9; depression 5.8 (3.4) vs. 6.5 (5.3) p=0.4. Whilst Minz et al (2005), reported a significant increase in depression scores as measured by a modified version of the Becks Depression Inventory (BDI); mean BDI scores at baseline vs. 3-month postoperative score: 0 (0-1) vs. 0 (0-2); p=0.04. Smith et al (2004) reported a striking increase in the point prevalence (2%-15%) and the twelve-month prevalence (10-31%) of psychiatric caseness between the preoperative period and the twelve-month postoperative period indicative of high incidence. The preoperative point prevalence for all of the disorders assessed was lower in the donors in comparison to the Australian population (2% vs. 11%) but the 12 month point prevalence was higher (15%) in the donors. Specifically, for anxiety and depression, the twelve-month point prevalence for the Australian population was 12% which is lower than the twelve- month point prevalence for the donors (18%).

Predictors of poor psychosocial outcomes.

Understanding the factors that lead to poorer psychosocial outcome will inform the psychological screening of potential donors and postoperative follow-up. Poor psychosocial outcome has been associated with the following: feelings of being abandoned after donation

(Brown & Sussman, 1982; Schover et al, 1997); poor recipient appreciation (Minz et al, 2005), unsuccessful transplantation (Fisher et al, 2005; Hivvas et al, 1980; Isotani et al, 2002 and Johnston et al, 1999) in particular recipient death (Minz et al, 2005 and Taghavi et al, 2001), persistent pain or prolonged hospitalisation in the donor (Minz et al, 2005) and previous preoperative psychiatric symptoms (Smith et al, 2004).

It is proposed here that a further and hitherto neglected factor may be the way in which the donor copes with the aftermath of donation. There is extensive evidence to suggest a relationship between coping style and outcomes relative to physical and psychological health (Beutler et al, 2003). Avoidant coping with the medical complaint, and the physical and psychological distress it causes, has been linked to negative outcomes such as increased pain in migraine sufferers (Marlowe et al, 2003), poorer prognosis in cardiac patients (Kelsey & Leitten, 1996), increased relapse in psychiatric cohorts (Lemke & Moos, 2002 and 2003), increased risk of depression in the general population (Cronike & Moos, 1995), and poorer treatment outcome (Beutler et al, 2003). By contrast, active coping has been linked with better outcomes (LaMontagne et al, 2004; Rosenberger et al, 2004). The impact of coping style on psychosocial outcome following live kidney donation has not been investigated and thus is the focus of the present research.

2. METHODOLOGY

2.1 AIMS AND HYPOTHESES

AIMS

- To investigate the postoperative quality of life of live kidney donors.

- To investigate which variables predict postoperative psychosocial outcome, with particular interest in the variable of coping style.
- To gather information regarding how individuals decide to become living kidney donors and how satisfied they are with their pre- and post-operative care.

HYPOTHESES

- The postoperative health-related quality of life of live kidney donors (as measured by the SF-36 and HADS) will not differ significantly from preoperative health-related quality of life.
- Adaptive coping style will correlate positively with quality of life after donation as measured by the SF-36 and HADS.

2.2 PLAN OF INVESTIGATION

INCLUSION CRITERIA FOR PARTICIPANTS

This study aimed to include:

- Live kidney donors who underwent a nephrectomy[8] at Manchester Royal Infirmary, Western Infirmary Glasgow and St. James University Hospital, Leeds between the period of January 2010 and October 2010 regardless of whether the kidney was then transplanted into the recipient or whether the transplant was successful.
- Were fluent in written and spoken English

[8] the removal of a kidney

- Were aged 18 years and above

RECRUITMENT PROCEDURE

Transplant coordinators are responsible for identifying a donor, providing support and education for the donor, all preoperative assessments, for organising organ and tissue retrieval, ensuring transplantation runs smoothly and undertaking a postoperative assessment. Therefore, as they represent the hub of the transplant team and have the most frequent contact with the donor, recruitment took place via the transplant coordinator. The recruitment procedure was as follows:

- Transplant coordinators made patient information sheets available to all kidney donors who met the inclusion criteria for the present study.
- Prior to nephrectomy, individuals who wished to participate signed a consent form and were given the donor questionnaire booklet 1 and a SAE for return to the principle researcher.
- The principle researcher contacted the renal unit to obtain the date of transplantation.
- Four weeks posttransplant the researcher mailed questionnaire booklet 2 and a SAE for return to the researcher.
- Participants who did not return a booklet within two weeks of transplant were again sent booklet 2 and a letter outlining the importance of the study and requesting return of the questionnaires.
- At the end of the study each participant and transplant coordinator were informed of the study's findings.

A four week follow-up was chosen for pragmatic reasons. The proposed three month follow-up (see appendix 4) was based on an extended period of data collection. However due to a delay in

obtaining Research and Development (R&D) approval for the study, the time available for data collection, given that the study was completed as part of the Doctorate in Clinical Psychology, was limited to six months. A three month follow-up, would allow only three months for recruitment. Therefore to increase the participation rate, a shorter follow-up period was chosen.

2.3 MEASURES

Questionnaire booklet 1 (appendix 3) contained a patient information sheet, demographic form, consent form and the following questionnaires:

- **The Donor Decision Control Scale**

The Donor Decision Control Scale is a three-item 5-point Likert scale indicating the extent to which donors involve a family member(s) in their decision to donate. Level one is a decision made independently by the donor; level two is a decision made by the donor after consulting with a family member(s); level three is a shared decision made by both the donor and a family member(s); level four is the donor relying on a family member(s) to make the decision after consulting with the donor; level five is the donor relying on a family member(s) to make the decision that the donor will donate. The test-retest reliability for this scale in a prospective study of donor decision-making and outcomes was 0.76 (Walton-Moss et al, 2007).

- **The COPE**

The COPE is a 60-item self-report multidimensional coping inventory, which assesses the different ways in which individuals respond to stress. The COPE was chosen as the means of measuring coping strategies over the more established Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988) because the WCQ has a single factor for assessing active coping

whereas the COPE has several separate scales for assessing different components of active coping. In this study the dispositional version of the COPE was used and participants were instructed to indicate the extent to which they use each response on a four-point Likert scale when they experience a stressful event. The full version of the COPE was used for the present study rather than the brief version of the COPE because the reliability coefficients for the brief version have all shown to only just exceed 0.50 (Carver, 1997) which is regarded as minimally acceptable (Nunally, 1978) whereas the reliability (internal consistency coefficients) for the full version is 0.62-0.92 (Carver et al, 1989).

- Five subscales of the COPE measure problem-focused coping, where individuals actively try to alter the stressful situation. These are as follows:

Active coping: the process of taking steps to remove or circumvent the stressor or to ameliorate its effects. Active coping involves initiating direct action, increasing one's efforts and trying to execute a coping effect in a stepwise fashion.

Planning: thinking about how to cope with the stressor. Planning involves producing action plans, thinking about what steps to take and how best to handle the problem.

Suppression of competing activities: putting other plans aside to concentrate on the problem.

Restraint coping: waiting until the appropriate time to act. This is an active coping strategy in the sense that the individual is focused on addressing the stressor but also a passive strategy in that they are using restraint and therefore not acting.

Seeking support for instrumental reasons: seeking advice, assistance or information.

- Five subscales measure emotion-focused coping. This is where an individual's actions are directed at regulating the emotional response to the stressor. The subscales of emotional-focused coping are as follows:

Seeking emotional social support: getting moral support, sympathy and understanding.

Positive reinterpretation and growth: focuses on managing the distress resulting from the stressor rather than managing the stressor itself. The value of this coping style is that it reduces distress but also intrinsically leads the individual to resume or continue problem-focused coping.

Denial: refusing to accept that a stressor exists or trying to act as though the stressor is not real.

Acceptance: the opposite of denial, therefore a functional coping response. The individual who accepts the reality of the situation is more likely to engage in attempts to address the stressors.

Turning to religion: turning to religion in times of stress.

- The following five subscales measure other less useful, coping responses:

Focusing on and venting of emotions: focusing on whatever distress or upset one is experiencing and venting those feelings. If the individual uses this time period to mourn and move, on this is a functional coping style. However, focusing on these emotions and prolonging this style of coping can impede adjustment and therefore be maladaptive.

Behavioural disengagement: akin to helplessness and is most likely to occur when the individual expects poor coping outcomes. It involves reducing one's efforts to deal with the stressor and even giving up the attempt to attain goals with which the stressor is interfering. This again is an example of maladaptive emotional coping.

Mental disengagement: This is where the individual tries to distract themselves from thinking about the goals with which the stressor is interfering by using such tactics as immersing

themselves in TV or sleep, daydreaming or taking part in activities that compete with the stressor.

Humour: coping by laughing at the situation or making jokes about it.

Alcohol and drug use: taking drugs or alcohol to improve mood or distract from the stressor.

Validity and reliability: With respect to concurrent validity, the active coping and planning subscales on the COPE correlate significantly with scales of optimism, control, self-esteem, hardiness and Type A personality (r= 0.20 - 0.32) and active coping inversely correlates with trait anxiety (r= -0.25). With respect to reliability, the internal consistency coefficients (cronbach's alpha) are 0.62 - 0.92. Test-retest reliability is between 0.42 and 0.77. The correlation between the scale items is 0.02-0.69, which has been interpreted as indicating that the subscales are empirically distinct domains (Bowling, 2005; Carver et al, 1989).

- **The Medical Outcomes Study 36-item Short Form Health Survey (SF-36)**

Within the renal transplant literature, the SF-36 is the most frequently used patient-reported measure of quality of life (Butt et al, 2008) because it contains eight of the most frequently measured health concepts (Bowling, 2005). The only areas included in widely used health surveys which are not included in the SF-36 are sleep adequacy, cognitive functioning, sexual functioning, health distress, family functioning, self-esteem, eating, recreation/hobbies, communication and symptoms/problems specific to a diagnosis. However, the SF-36 correlates substantially with these omitted health concepts (r=0.4 or greater) and with the frequency and severity of many specific symptoms and problems (Ware et al, 1993 & 1994). The only known exception is sexual functioning which correlates weakly with the SF-36 scales.

Psychological wellbeing: the SF-36 assesses 4 components of mental health: (1) energy and fatigue (vitality domain) (2) limitations on social functioning because of physical or emotional problems (social functioning domain) (3) limitations on usual activities because of emotional problems (role-emotional domain) and (4) psychological distress and well-being (mental health domain).

Physical wellbeing: the SF-36 assesses 4 components: (1) physical functioning, (2) limitations on usual activities because of physical problems (role-physical domain), (3) bodily pain and (4) general health.

Scoring and Interpreting results: Domain scores are expressed as a value between 0 and 100, with greater scores representing better health. Domain scores are interpreted using the following criteria: a difference of 5-points in any domain is considered minimally clinically and socially relevant and a difference of ten-points considered moderately clinically and socially relevant (Ware et al, 1994). The Mental Health Component Summary Scale (MCS) and the Physical Health Component Summary Score (PCS) represent an overall view of mental and physical health respectively.

Algorithms for the calculation of the PCS and MCS involve factor analysis of normative datasets gained from population norms which can be applied to all datasets throughout the world. Jenkinson (1999) found that when comparing the pre- and post-operative psychosocial outcomes of congestive heart failure patients, the calculated MCS, PCS and corresponding effect sizes were not significantly different depending on whether they used UK or US population norms.

Therefore, this study will calculate the MCS and PCS as advised in the SF-36 manual using US normative data.

Reliability: The internal consistency reliability is 0.92 for the PCS and 0.89 for the MCS. The test-retest reliability for an interval of two weeks is 0.89 for the PCS and 0.80 for the MCS (Ware et al, 1994)

- **Hospital Anxiety and Depression Scale (HADS)**

The HADS (Zigmond & Snaith, 1983) is a 14-item self-report measure designed to screen for the presence and severity of mood disorders in medically ill patients on a four-point Likert scale. The concurrent validity of the scale was tested by comparing the results of clinical assessment with the HADS scale results. This yielded significant correlations, 0.54 for anxiety and 0.79 for depression (Zigmond & Snaith, 1983).

Questionnaire pack 2 (appendix 3) : four weeks post-operative, participants completed the SF-36 and HADS again in order to compare health related quality of life after donation with pre-operative health related quality of life. In addition participants completed the following :

- **The Living Donor Survey**

The Living Donor Survey is a 60-item questionnaire designed to measure attitude toward living kidney donation, satisfaction with donation education, hospital care, care after discharge and health after surgery (Beavers et al, 2001). In a study of donor decision-making and outcomes the internal consistency of the dimension that measured attitude to living donation was 0.75 using Cronbach's alpha (Walton-Moss et al, 2007)

2.4 DESIGN

Data Analysis

A paired t-test compared donors' pre- and post-operative SF-36 scores. Pre- and postoperative SF-36 scores were compared to population norms from The Oxford Healthy Living Survey (Jenkinson et al, 1993). SF-36 domain scores were interpreted using the following criteria: a difference of five points in any domain was considered minimally clinically and socially relevant, and a difference of ten points considered moderately clinically and socially relevant (Ware et al, 1994). The study by Smith et al (2003 & 2004) was the only prospective study of psychosocial outcomes of live kidney donors which calculated effect size and this study did so using Glass' method (Glass & Hopkins, 2008). To maintain consistency and allow comparison between publications, effects size was calculated using the same method whereby the effect size was calculated as mean at follow-up subtracted from the mean at baseline, divided by the standard deviation for the baseline. Effect sizes were classified as follows: 0.2-0.49 equated to a small difference, 0.5-0.79 equated to a moderate difference and 0.8 or above equated to a large difference (Cohen, 1988).

With respect to the HADS, for the Anxiety and Depression scales, scores of between 8 and 10 identified mild cases, 11-15 moderate cases and 16 or above, severe cases (Zigmond & Snaith, 1983). A paired t-test compared donors' pre- and post-operative HADS scores. Changes in symptom severity and prevalence were also recorded.

Analysis of the relationship between coping strategy and psychosocial outcome involves multiple statistical comparisons. Multiple statistical comparisons increase the probability of making a Type I error. In order to reduce the chance of making a Type I error, a more conservative significance level of 0.01 will be applied this analysis.

Statistical Power and sample size

Aguiar et al (2007) measured the psychosocial outcomes for live kidney donors' 1month postoperative using the SF-36. The authors presented the results in accordance with surgical access, lombotomy or subcostal incision. The effect sizes calculated from the data in this paper and the sample size required to detect a statistically significant difference assuming the convention of $\alpha = 0.05$ and power of 0.8 are presented in Table 2.

Insert Table 2 here

Aguiar et al (2007) did not present the MCS or the PCS scores. However, Bergman et al (2005) reported the MCS and PCS for 35 live kidney donors 4-weeks post-operative. The effect sizes calculated from this paper and the sample size required to detect a statistically significant difference assuming the convention of $\alpha = 0.05$ and power of 0.8 are presented in Table 3. All donors in this study underwent laparoscopic nephrectomy.

Insert Table 3 here

Considering the data from each of these tables, it can be seen that with a sample of 20 participants, the study had enough power to detect a statistically significant difference for all of the variables on the SF-36 presented in bold text. For all the other variables recruitment would

have needed to be extended beyond one year in order to obtain a participant rate high enough to detect a statistically significant difference. As this would be impractical for the present research study, which is carried out as part of the Doctorate in Clinical Psychology whereby recruitment should last over a period of six months, the aim was to obtain twenty complete datasets. Regardless of sample size and statistical power, the study was able to describe the number of individuals with a clinically and socially relevant change in SF-36 scores postoperatively and also the change in severity of anxiety and depression as determined by the HADS.

3. RESULTS

Recruitment and retention

Figure 1 provides a flow chart of recruitment and retention. One hundred and eight living kidney donor transplants took place during the period of recruitment. MRI did not approach all living donors about the study due to appropriateness. Twenty agreed to participate and returned baseline questionnaire pack. However, as all donors met the inclusion a criterion, the participant rate is estimated at 19%.

Four participants erroneously completed their baseline questionnaires post-transplant, and therefore their HADS and SF-36 questionnaires were unusable[9]. Follow-up questionnaires were sent to all twenty participants. Individuals who returned a baseline questionnaire pack that could

[9] The baseline SF-36 and HADS questionnaires must be completed before transplant to enable comparison between the preoperative health related quality of life and quality of life four weeks after transplant.

not be used were still sent the follow-up questionnaire pack in order to obtain a completed Living Donor Survey. Fourteen participants returned the follow-up questionnaire pack.

With respect to analysis, as can be seen from Figure 1, complete data were available for thirteen participants and therefore analysis was based only on these individuals.

The demographic data for the final sample are represented in Table 4. The majority (11 out of 13) of the donors were biologically related to the recipient. Eleven of the donors were in employment; two in part-time and nine in fulltime employment. The sample was predominately male, white British and married. No information was available on those who declined to participate in the study or were lost to follow-up due to restrictions in ethics approval.

The follow-up questionnaires were mailed to all participants three weeks after donation and donors were asked to complete the questionnaires on the fourth week following donation. The dates on the questionnaires indicated that five donors completed the follow-up questionnaires four weeks postoperative and four donors completed the questionnaires five weeks postoperative. A reminder letter was sent to donors who had not returned follow up questionnaires by six weeks postoperative. Subsequent to this, three donors returned their questionnaires late; at seven, thirteen and fifteen weeks postoperative. The data for these donors are included in the analysis and acknowledged in the discussion chapter as a study limitation. The correlation between number of weeks to return follow-up questionnaires and postoperative outcome were as follows:

MCS r= -0.7[10], p=0.02; PCS r=0.66, p=0.85; HADS anxiety score r=0.8, p=0.001; HADS depression score r=0.8 p=0.001. This suggests that poorer psychosocial outcomes were associated with returning the follow up questionnaires late.

Insert Table 4 here

Donor decision-making

The majority of participants (11 out of 13) reported involving someone else in their decision to donate a kidney. All eleven donors were either married or cohabiting and 10 out of the eleven involved their spouse or partner in their decision to donate a kidney. One married donor involved only their cousin in the decision-making process. The majority (7 out of 13) of donors believed that they made their decision to donate independently. Four made the decision to donate after considering others' opinions and two shared the responsibility for the decision with family or friends. No donor believed that the decision to donate was made by someone else. Individuals who involved another person in their decision to donate were asked to indicate how supportive this person was of their decision to donate on a ten-point Likert scale ranging from "not at all supportive" (scored 1) to "very supportive" (scored 10). Ten of the eleven donors who involved someone in their decision to donate reported that this person was supportive whilst one

[10] Higher MCS and PCS scores indicated better psychosocial outcome whilst higher HADS scores indicate more symptoms of anxiety and depression.

individual reported that this person was "not at all supportive" (mean score = 8.5 standard deviation 2.6; ten donors scored this questions as eight or above).

Donors were asked in The Living Donor Survey if at any time they felt pressurised to donate. Only one donor responded positively to this question and reported that they had felt pressurised by the transplant team, the recipient and family and friends (Table 5). However this donor responded strongly agree to the question "knowing what I know now, I would donate again."

Insert Table 5 here

Donors' satisfaction with donation education

The key findings from the Living Donor Survey are presented in Table 6. The majority of donors reported that the process of donation, possible complications including risk of death, and the recovery process had been explained to them clearly. Furthermore all of the donors reported that any questions they had with respect to donation were answered by the renal team before surgery. All but one donor reported that the renal team addressed any complaints or needs that they expressed whilst in hospital or after discharge. Possibly as a consequence of the clarity of information that donors received, the majority of donors reported that the amount of pain following surgery (11 out of 13), the length of their hospital stay (13 out of 13) and recovery time (7 out of 13) was consistent with or less than expected.

Insert Table 6 here

Health related quality of life

The mean length of hospital stay was 6.2 days, standard deviation 1.8, and ranged from 5 days to 11 days. Five donors reported experiencing postoperative complications; 1 had blistering from their wound dressing lasting three weeks, 1 had blood in their urine for three weeks, 1 experienced a chylothorax[11] and breathing difficulties lasting three days, 1 had subcapusalar splenic hematoma[12] which resulted in a spleenectomy and 1 had a wound infection and a urine infection lasting two weeks. The latter three of these individuals were readmitted to hospital following discharge for complications associated with the donation process. Therefore the postoperative complication rate reported in this study was higher than that previously reported; Nolan et al (2004) reported that the postoperative complication rate was 0.3% whilst Ibrahim et al (2009) concluded that kidney donors have a health status similar to that of the general population following donation.

Preoperative and postoperative scores on the SF-36 are presented in Table 7. Following donation, donors as a whole presented with significant reductions in the Physical Component Summary scale (PCS) and all the corresponding domains with the exception of the general health domain. For the general health domain, the p-value was 0.06 and therefore close to statistical significance. Given the small sample size in this study this result should be considered worthy of

[11] chylothorax (or chyle leak) is where excess fluid accumulates in the pleural cavity of the lungs
[12] bleeding from the spleen usually resulting in the removal of the spleen (spleenectomy)

further investigation. With respect to the effect size, for the PCS and all of the corresponding domains the decline was large (-0.82 to 2.22).

Table 7 also details the number of individuals who have postoperative SF-36 domain scores that are defined as clinically and socially relevant, whether they are mildly or moderately clinically and socially relevant and whether the postoperative scores reflect an improvement or a decline in functioning [13]. As can be seen from Table 7, for the majority of donors the decline in physical functioning, as measured by the SF-36 PCS and the corresponding domains, was moderately clinically and socially relevant.

With respect to the Mental Health Component Summary scale (MCS) and the corresponding domains, the only significant decrease for the group as a whole was seen in the vitality domain; donors reported significantly less energy and more fatigue following donation with a large effect size. For ten of the donors the decline in vitality was moderately clinically and socially relevant. Although mean postoperative scores for the domains of social functioning, role-emotion and mental health did not differ significantly from the mean preoperative scores, analysis of the individual scores for each donor indicates that for many there was a clinically and socially relevant decline in these domains following donation (Table 7).

[13] a difference of 5-points in any domain is considered minimally clinically and socially significant and a difference of ten-points considered moderately clinically and socially significant (Ware et al, 2003)

The postoperative MCS correlated positively with the postoperative PCS; correlation coefficient = 0.37, p=0.22. This suggests that as donors physical health improves so did their psychological wellbeing, and conversely, as their physical health deteriorated so did their psychological wellbeing. Likewise as the donors' mental health deteriorated they reported lower physical functioning. It is important to note however that this correlation is not statistically significant. There were eight donors within the sample who reported clinically and socially relevant improvements in health-related quality of life following donation. Table 8 outlines in which domain improvements were reported. Each of these donors donated to a family member and therefore it is possible that the scores improved after donation due to the improvement in the recipients' health and the consequential reduction in worry or caring duties in the donor. Support for this hypothesis comes from the fact that seven donors reported clinically and socially relevant reduction in psychological distress (mental health domain) following donation whereas only three reported an increase. Furthermore before donation, donors reported that their social functioning was lower than that of the UK population indicating that emotional distress was responsible for them spending less time in social activities (Table 7).

Insert Table 7 and 8 here

A score of 42 or less on the MCS is indicative of a diagnosis of depression. (Ware et al, 1994). Preoperatively three donors had a MCS score below 42, only one of these individuals, however, continued to have a score below 42 following donation. However, postoperatively, four new donors fell below the cut off point for psychiatric caseness. Within this study psychiatric diagnosis, in particular a diagnosis of anxiety and depression was detected by the HADS.

Postoperative anxiety scores were lower than preoperative anxiety scores, but this result failed to reach statistical significance (mean anxiety score: preoperative vs. postoperative= 6.4, sd 4.4 vs 4.8, 4.2, t=1.33 p=0.2). Five donors were categorised as anxiety cases before donation. Following donation, two of these donors were no longer cases and the severity of anxiety in two of these donors decreased. There were two new cases of anxiety following donation; two donors did not reach anxiety caseness on the HADS before transplant but met the HADS criteria for mild anxiety following donation.

With respect to depression, for the group as a whole, scores on the HADS depression inventory increased following donation (mean depression score: preoperative vs. postoperative= 2.7, sd 3.3 vs 3.9, 4.4, t=1.1 p=0.3). Again this result failed to reach statistical significance. Before donation only one donor met the HADS criteria for depression. Following donation this donor continued to meet the HADS criteria for moderate depression and two new donors met the criteria for mild depression.

Factors associated with postoperative psychosocial outcomes

Pre-operative SF-36 scores and post-operative health-related quality of life

The results presented in Table 9 indicate that postoperative psychosocial outcome as measured by the SF-36 is not significantly correlated with pre-operative scores on the SF-36 or the HADS.

Donor decision-making and post-operative health-related quality of life

As none of the donors in the study relied on another to make their decision to donate it is not possible to assess the impact of the decision-making process on psychosocial outcome. However, as shown in Table 11, increasing feelings of pressure to donate did not correlate with

psychosocial outcome. Therefore it may be hypothesised that relying on others to make the decision to donate will not lead to poorer psychosocial outcome.

Coping and post-operative health-related quality of life.

SF-36: Significant associations were found between coping strategies and post-operative MCS and PCS scores (Table 10).

When the significance level was set at $p \leq 0.05$, active coping, planning and seeking instrumental support were significantly associated with higher MCS scores. Mental disengagement showed a trend association with lower MCS scores ($p<0.1>0.05$). PCS scores were also positively associated with planning and, marginally, with turning to religion and acceptance. There was also a marginal negative association between PCS and mental disengagement.

However, when the significance level was set at $p \leq 0.01$ to take into account the risk incurring a type I error due to multiple comparisons, only active coping was significantly associated with higher MCS scores.

HADS: When the significance level was set at $p \leq 0.05$, post-operative anxiety was associated with seeking instrumental social support and, marginally, with active coping. In the case of post-operative depression, there were marginal negative associations with active coping and seeking emotional support. However, when the significance level was set at $p \leq 0.01$, none of the coping strategies investigated significantly correlated with post-operative HADS scores.

Coping and pre-operative health-related quality of life

SF-36: Significant associations were found between coping strategies and preoperative MCS and PCS scores. When the significance level was set at $p \leq 0.05$, active coping and humour were significantly associated with higher MCS scores. By comparison lower MCS scores were significantly associated with denial (Table 10). Lower PCS scores were also significantly associated with seeking instrumental social support and, marginally, with mental disengagement (Table 10). However, when a more conservative significance level of $p \leq 0.01$ was adopted to reduce to chance of a type I error, only seeking instrumental social support was significantly associated with lower PCS scores.

Insert Tables 9, 10 and 11 here

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4. DISCUSSION

Donor's health-related quality of life was the primary outcome measure of the current study. The results indicate that live kidney donation had a significant adverse affect on the physical wellbeing of the donors; the postoperative scores on the PCS and all of the corresponding domains were significantly lower and with a large effect size. To give perspective, postoperative scores on the PCS and all the corresponding physical health domains, with the exception of general health, were lower than the scores obtained by the Oxford Healthy Living Survey from a sample with long-standing illness (Jenkinson et al, 1993).

Potentially as a consequence of increased body pain and decreased physical functioning, postoperatively, donors reported significantly more fatigue and less energy (vitality domain) and

a significant reduction in social functioning due to physical and emotional problems. This result is not surprising given that the donors had undergone major surgery. Furthermore, given that all but two donors donated to a direct family member, it is possible that the donors were unable to fully recuperate due to having to care for the recipient or having reduced practical support from other family members who may have been caring for the recipient. The fact that the majority donated to a family member may also explain why the majority of donors reported a clinically and socially relevant decline in usual activities as a consequence of emotional problems (role emotion domain) despite only three donors reporting a decline in their mental health postoperatively.

With respect to psychological wellbeing, donors' scores on the MCS did not differ significantly from their preoperative scores. With respect to anxiety, for the group as a whole postoperative HADS anxiety scores were lower and the severity and prevalence of anxiety symptoms reduced. This result should be interpreted with caution, as it is possible that preoperative anxiety scores in the donor do not represent baseline scores but rather are inflated due to concerns for the ill health of the recipient and may also reflect the donors' anxiety over their impending surgery. For depression there was only a marginal increase in HADS depression scores.

Analysis of each individual's outcomes indicated that there was a marked difference in the impact of donation. Whilst the majority were not adversely affected by donation and, more specifically, for eight donors there was an improvement in psychological functioning (Table 8), for some individuals there was an emotional cost to kidney donation. Three donors reported a decline in mental health and there were two new cases each of anxiety and depression.

Identifying why some donors have a poorer outcome is essential to screening of potential donors. The results suggest that poor psychosocial outcome following donation was marginally associated with relying on mental disengagement as a coping strategy. However, improved outcome in the postoperative period was associated with seeking social support whereas this coping strategy was associated with poorer wellbeing in the preoperative period. One possible explanation for this may be that since the donors were donating to a family member, seeking sympathy and moral support was considered inappropriate by others during the preoperative period because they had not undergone any surgical procedure and, unlike the recipient, the donor was in good health. By comparison, after donation others may have been more amenable to offering understanding and sympathy due to the donor having undergone major surgery and with considerable pain and discomfort.

4.1 Comparison with previous research

The study confirms and extends the results of previous prospective studies. With respect to physical wellbeing, four prospective studies measured the physical health of donors four week after live kidney donation using the SF-36 (Aguiar et al, 2007; Bargman et al, 2006; Bergman et al, 2006; Kok et al, 2006). As in this study, Bergman et al (2005) reported that the postoperative PCS was significantly lower than the preoperative PCS with a large effect size ($p=<0.0001$, effect size -2.29). The results of Bargman et al (2006) further supported this finding; postoperative PCS was significantly lower than the preoperative PCS ($p<0.05$) with a large effect size (effect size: standard laparoscopic nephrectomy= -1.89, hand assisted laparoscopic nephrectomy = -1.96). With respect to the individual domain scores, as in this study, one month after donation the domain scores for physical functioning, role physical and bodily pain are

significantly lower than preoperative scores (Aguiar et al, 2007; Bergman et al, 2006 and Kok et al, 2006) with a large effect size (Aguiar et al, 2007). Aguiar et al (2207) also supported the finding of this study in that, for the majority of donors, the decline in these domains was clinically and socially relevant. The current study reported that one month after donation, donors reported a significant decline in their general health with a large effect size. Furthermore, for seven of those donors the decline was socially and clinically relevant. By comparison, Aguiar et al (2007) and Bergman et al (2006) found that the decline in general health was not statistically significant (p-value for Bergman et al, 2006= 0.7; p-value for Aguiar et al, 2007= 0.9).

With respect to psychological wellbeing following donation, Smith et al (2004) found that in the main donors' psychological health was not adversely affected by donation, hence supporting the present study. However, there was a subset of donors who either experienced a significant reduction in their MCS or reported improved psychological wellbeing following donation. Previous studies measuring psychosocial outcomes one month postoperatively have also found that the dimension of vitality and social functioning show greatest amount of change from the postoperative period (Aguiar et al, 2007; Bergman et al, 2005; Kok et al, 2006; see Tables 3 and 4). In the current study, the postoperative decline in the dimension of role emotion failed to reach statistical significant despite five donors reporting that their decline was socially and clinically relevant. Again, this result is consistent with previous research; a statistically-significant decline in the dimension of role emotion was reported by Aguiar et al (2007), Bergman et al (2005) and Kok et al (2006). With respect to the dimension of mental health, the present study found that the majority of donors reported clinically and socially relevant improvement in this domain. Bergman et al (2005) and Minnee et al (unpublished) similarly found that mental health

improved following donation; however, Aguiar et al (2007) and Kok et al (2006) reported a significant reduction in this domain at one month postoperatively.

Only two studies have evaluated the level of anxiety and depressive symptoms one month after live kidney donation (Taghavi et al, 2001; Yoo et al, 1996). With respect to anxiety the result of this study is inconsistent with that of Taghavi et al (2001) who found that preoperatively all donors were within the normal range for anxiety symptomatology as measured by the SCL-90, but, postoperatively, six donors met the criteria for anxiety disorder. Yoo et al (1996) reported that donors were significantly more anxious about death following donation. By comparison this study found that donors' postoperative scores on the HADS indicated that they were less anxious and that prevalence of anxiety disorder decreased following donation. With respect to depression, the present study supports the finding by Taghavi et al (2001) that following donation the prevalence of depression amongst live kidney donors increased. By comparison, Yoo et al (1996) found that postoperative scores on the BDI were equivalent to preoperative scores.

It has been argued that donors' preoperative health-related quality of life scores will be higher than those of the general population, firstly, because they are a select sample of healthy individuals, and, secondly, because preoperatively they are encouraged to achieve a high level of fitness before donation. Several studies have reported population norms alongside preoperative SF-36 scores for their sample and found that, preoperatively, donors' scores are higher for the MCS and PCS and all corresponding domains (Bergman et al, 2005; Smith et al, 2004 and Walton-Moss et al, 2007). The findings of this study, however, do not support these findings. When donors' preoperative scores were compared with population norm scores reported in The

Oxford Healthy Living Survey (Jenkinson et al, 1993) only the dimension of role physical, bodily pain, general health, role emotion and vitality were higher than population norms. By comparison, the dimensions of physical functioning and social functioning were lower whilst mental health was comparable with population norms.

4.2 Strengths and Limitations

The main limitation of this study concerns the small sample size (n=13) which is considerably smaller than other prospective studies. In sixteen published studies, participation rates varied from 80% (Walton-Moss et al, 2007) to 100% (Aguiar et al, 2007; Minnee et al, 2008a)[14]. Whilst retention rates ranged from 100% four week postoperatively (Minnee et al, 2008a) to between 82% (Lumsdaine et al, 2005) and 100% (Minnee et al, 2008) one-year postoperatively[15]. It is possible however, that high retention and participation rates were obtained by previous researchers because assessments were carried out by the renal team and therefore donors were more willing to participate and questionnaires were part of the routine clinical assessment. The present small sample introduces the possibility of a type II error. Furthermore, the small sample size prevents investigation of how the donor-recipient relationship may impact on the decision-making process, satisfaction with donation and psychosocial outcome. On the positive side however, despite the small sample size the study showed several statistically significant results of importance, identified individuals who had a clinically and socially relevant change in psychosocial functioning, and, a change in prevalence of anxiety and depression symptoms.

[14] Walton-Moss et al (2007) n=52; Aguiar et al (2007) n= 60; Minnee et al (2008) n=60
[15] Lumsdaine et al(2005) participation n=52 and retention n=40

Another limitation of the study involves selection bias. It is possible that donors with adverse outcomes were less willing or able to participate. The correlation between the number of weeks to return a questionnaire and the MCS and HADS score may support this hypothesis. Furthermore, Bergman et al (2005) noted that although donors who withdrew from the study postoperatively did not differ with respect to demographic and intraoperative data, they did have a lower postoperatively quality of life. Unfortunately, no other study reported on the outcome of those who refused to participate in the study or were lost to follow up despite this possibly being obtainable from medical record or follow up clinic reports. Therefore, this is an area that warrants further investigation.

The validity of the HADS and SF-36 scores in the preoperative period require attention. It is possible that, pre-transplant, donors under-report psychological problems and difficulties in functioning due to the desire to become a donor. Whereas, following transplantation, the donors do not have to meet an inclusion criterion and therefore provide more reliable reports. With the exception of Smith et al (2004), the evaluation of functioning and psychiatric caseness has been assessed by self report. In Smith et al (2004) the current and past (last 12 months and lifetime) psychiatric caseness was established by a psychiatrist using information from a semi-structured interview combined with information from the self-completed patient-health questionnaire. Furthermore, donors and their family in this study were given an education session stressing the importance of mental wellbeing and the implication of hiding symptomatology, and were informed that the psychiatrist had access to medical records and interviews conducted over the preceding months. Smith et al (2004) indicated that live kidney donation has a negative impact on the quality of life for some donors which can last up to 12-months post transplant.

Furthermore, unlike others, this study reported a striking increase in point prevalence and incidence post transplant. Unfortunately, Smith et al (2004) did not report the accuracy of the self-completed assessment in comparison to the review of medical records and assessment by the psychiatrist. The present study may have overcome this bias to a certain extent, as the participant information sheet made it explicit that the research was independent of the renal team

It can also be argued that the donors' pre-operative level of functioning and anxiety and depression scores are not reflective of their "normal self" but rather reflect the functioning of (1) an individual who has a family member with end-stage renal disease facing a potentially unsuccessful transplant, and (2) an individual who in the near future will undergo major surgery. It is difficult to overcome this limitation as one cannot administer questionnaires before the recipient became unwell or before the donor decided to donate. Perhaps one way to overcome this problem is to compare post-operative scores to population norms; however as discussed before, this introduces other limitations (Walton-Moss et al, 2007).

Finally, post-operative assessment was made only four weeks after donation therefore it remains unclear whether any adverse effects of donation are persistent.

4.3 Conclusion

The physical health of live kidney donors is adversely affected by live kidney donation. Four weeks postoperatively live kidney donors reports their physical health as worse than those with long-standing illness. However, this may be expected given that the donors were being asked to rate their physical health four weeks after undergoing major surgery. The psychological wellbeing of the majority of donors appears to be largely unaffected by live kidney donation.

However, there is a minority who pay an emotional cost. Nonetheless, all donors reported that in retrospect, they know now they would donate again and would recommend live kidney donation to others.

The findings of this study suggest that the donor's coping strategy influences psychosocial outcome, but the conclusion should be interpreted with caution due the small sample size and therefore the possibility of a type I error.

4.4 Implications for development of renal services

The majority of donors involved a family member in their decision to donate, thus highlighting the need for the renal team to involve family members in the evaluation and education sessions provided for the donor. There may be a case for developing educational materials for donors' family members that highlight the factors to be considered in the decision making process and also guidance on how they can support the donor postoperatively

The extent of psychological morbidity and level of anxiety and depression indentified in this study support the need for donors' psychosocial outcomes to be to be monitored following transplant. Whilst, this study was unable to assess donors' psychological wellbeing at various points throughout the post transplant period, the results of Smith et al (2004) would, however suggest that it would be essential to offer routine follow up appointment for 12 months for some donors. The SF-36 has been shown in this study to be an appropriate and useful tool for assessing post-operative psychological and physical wellbeing. Furthermore, donors appear to be willing to complete this questionnaire and, as Smith et al (2003) reported, donors find it a useful indicator of the issues that are important to them. Therefore, where it is not possible to offer all donors a

follow- up appointment by the renal team, donors could be screened for the suitability for referral to the clinical psychology service by mailing the SF-36 questionnaire at intervals throughout the post-transplant period.

4.5 Future research

A greater understanding of the impact of live kidney donation will be achieved from a larger, multi-centre prospective study which follows donors regularly over a prolonged period of time. Such a study should gather information about those who do not participate or are lost to follow-up. To reduce bias, assessment should be carried out by an independent researcher. Such a study would facilitate identification of the risk factors for poor psychosocial outcome, support the screening of potential donors and clarify the role of Clinical Psychology with the transplant team.

With respect to assessing donor satisfaction with donor education and donor decision-making process, individuals who do not proceed to donate for medical or personal reasons should also be included. Particular attention should be paid to donor decision-making and satisfaction dependent on the donor- recipient relationship. For example, further research might consider those donors who donate altruistically or to a recipient with whom they do not have an emotional or biological relationship, to examine whether they involve a family member in the decision to donate, and have the same positive sense of self following donation.

Table 1: Donor-recipient relationships

Definition	Traditional compatible	Incompatible	Paired	Altruistic
Description	Donor is blood group and tissue compatible with the recipient	Donor may be blood group and/or tissue incompatible with the recipient, but with plasmapheresis* treatment transplantation my occur	A blood group incompatible donor and recipient will be matched with another incompatible blood group donor and recipient, and the kidney will be exchanged between the two compatible pairs.	A volunteer donates a kidney anonymously to an unknown recipient.
Typical relationship	Genetically related.	Family, friend or anonymous donor	Usually anonymous donor	Anonymous donor

*Plasmapheresis is the removal of antibodies that destroy organs from people with different blood types. These antibodies can rapidly destroy a transplanted kidney.

Table 2: Results of Aguiar et al (2007)

SF-36	Effect size	Sample req. to find a statistically significant result
***Physical functioning**	**L:-2.6** **S:-2.3**	**L:3** **S:3**
***Role physical**	**L:-1.3** **S:-1.7**	**L:6** **S:4**
***Bodily pain**	**L:-1.2** **S:-0.9**	**L:6** **S:10**
General health	L:0.1 S:0.06	L:620 S:1719
***Vitality**	**L:-0.8** **S:-0.6**	**L:12** **S:19**
***Social functioning**	**L:-1.9** **S:-0.6**	**L:4** **S:19**
Role emotion	L:-0.97 S:-0.3	L:9 S:71
Mental health	L:-0.3 S:-0.4	L:71 S:41

*SF-36 variables whereby a sample size of 20 will have sufficient power to detect a statistically significant difference.

Table 3: Results for Bergman et al (2005)

SF-36	Effect size	Sample req. to find a statistically significant result
MCS	0.14	317
***PCS**	**-2.29**	**4**

* SF-36 variables whereby a sample size of 20 will have sufficient power to detect a statistically significant difference.

Figure 1: Flow chart of recruitment and retention

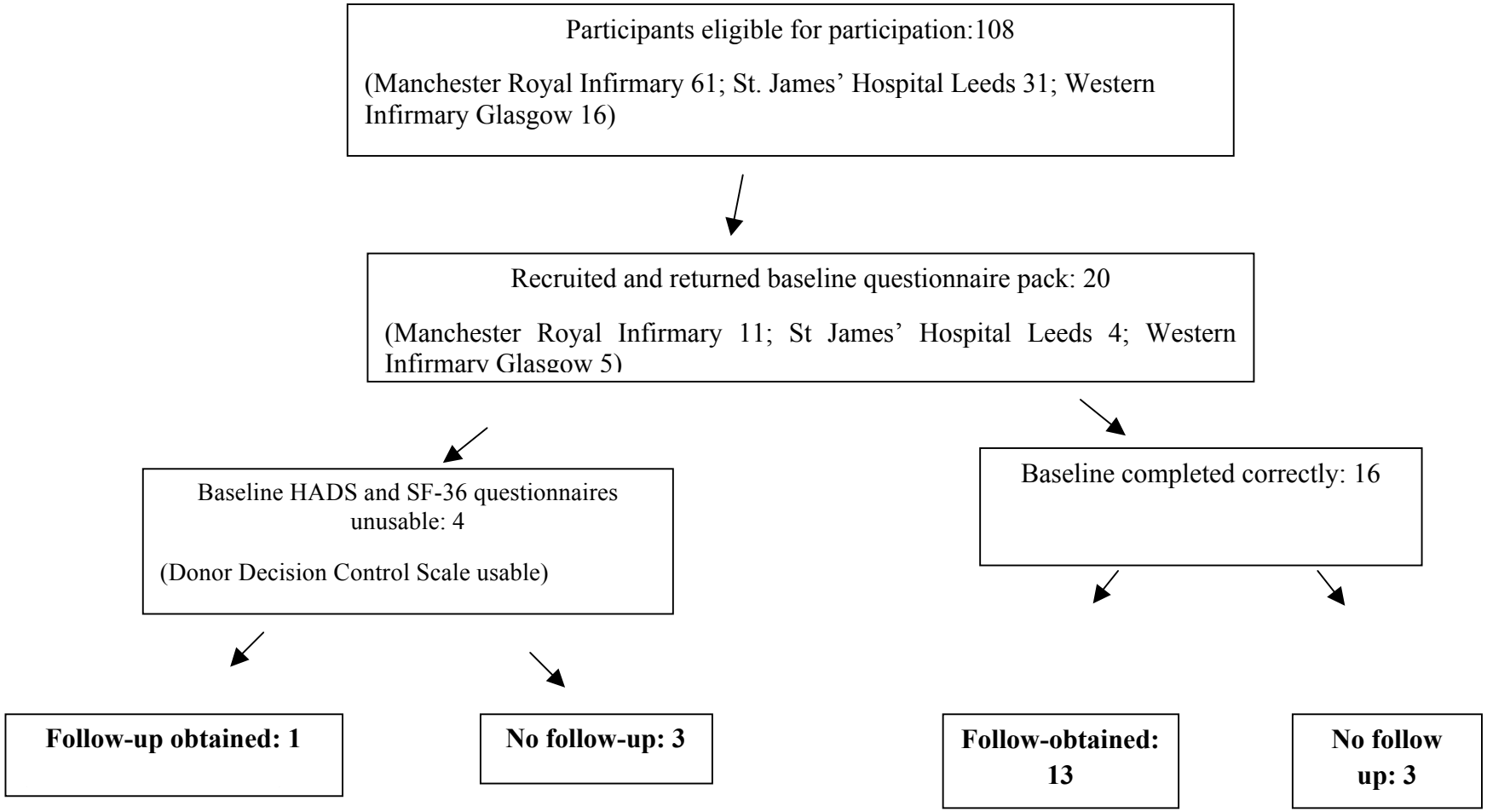

Table 4: Demographic information for the sample included in the analysis.

Number of subjects	13
Referring hospital	Manchester Royal Infirmary:8 St. James' Hospital, Leeds: 2 Western Infirmary Glasgow: 3
Weeks since transplant **Mean (±SD)** **Range**	 6.2 (3.7) 4- 15
Age at transplant (years) **Mean (±SD)** **Range**	 51.64 (7.70) 39.0 -62.16
Gender (male: female)	8:5
Ethnic origin	White British: 12 Black- African:1
Marital status	Married: 11 Cohabiting: 2
Relationship with recipient	Spouse: 2 Son/daughter: 6 Parent: 1 Sibling: 1 Other relative: 1 Pooled donation: 1 Altruistic donation: 1

Table 5: Donors decision making

Aspect evaluated	Response (n=13)
Involved someone else in the decision to donate	Yes: 11
Person involved in decision to donate (n=11)	Spouse/partner: 10 Cousin: 1
Decision making process	Decision made independently: 7 Decision made with consideration of others opinions; 4 Decision jointly made with family and friends: 2
I felt pressurised to donate by the transplant team	Disagree: 12 Agree: 1
I felt pressurised to donate by the recipient	Disagree: 12 Agree: 1
I felt pressurised to donate by family and friends	Disagree: 12 Agree:1

Table 6: Donors' satisfaction with information given by the renal team with respect to donation

The information that I received about the surgery was	Very clear: 10 Moderately or somewhat clear: 2 Somewhat vague: 1
The information I received about the recovery process was	Very clear: 5 Moderately or somewhat clear: 5 Moderately or somewhat vague: 3
The information I received about possible complications of surgery was	Very clear: 2 Moderately clear: 11
The information I received about the risk of death was	Very clear: 11 Moderately or somewhat clear: 1 Moderately or somewhat vague: 1
Before proceeding with surgery my questions were	Completely answered: 11 Moderately or somewhat answered: 2
When I expressed needs or complaints in hospital these were	Completely answered: 11 Moderately or somewhat answered: 2
When I expressed needs or complaints after discharge these were*	Completely answered: 7 Moderately or somewhat answered: 2 Moderately or somewhat ignored: 1
Amount of pain after surgery was	Much more than expected: 1 More than expected: 1 As expected: 5 Less than expected: 4 Much less than expected: 2
Length of hospital stay was	As expected: 5 Fewer days than expected: 5 More days than expected: 3

* 10 participants answered this question

Table 7: Comparison of pre- and post-operative scores on the SF-36 and population norms from The Oxford Healthy Living Survey

Scale	Norms Mean ±SD	Preoperative Mean ±SD	Postoperative Mean ±SD	Statistical Significance	Effect size	Clinically and socially relevant
MCS	-	49.08 (12.0)	43.07 (15.6)	t=-1.27, p=0.229	-0.5	-
PCS	-	55.1 6 (7)	41.48 (7.1)	**t=5.05 p=0.000**	-1.95	-
Physical functioning	88.4 (17.9)	86.54 (18.64)	68.08 (16.01)	**t=3.18 p=0.008**	-0.99	Mild improvement: 0 Moderate improvement: 1 Mild decline: 1 Moderate decline: 9
Role-physical	85.8 (29.9)	89.42 (21.7)	41.35(36.22)	**t=3.69 p=0.003**	-2.22	Mild improvement: 0 Moderate improvement: 1 Mild decline: 0 Moderate decline: 10
Bodily pain	81.5 (21.6)	84.46 (26.11)	52.77 (6.82)	**t=2.80 p=0.016**	-1.23	Mild improvement: 0 Moderate improvement: 2 Mild decline: 0 Moderate decline:11
General health	73.5 (19.9)	82.9 (8.87)	75.62 (13.85)	t=2.06 p=0.06	-0.82	Mild improvement: 1 Moderate improvement: 1 Mild decline: 2 Moderate decline: 5
Vitality	61.1 (19.6)	69.7 (15.7)	46.6 (24.95)	**t=3.0, p=0.01**	-1.47	Mild improvement: 0 Moderate improvement:2 Mild decline: 1 Moderate decline: 10
Social functioning	88.0 (19.5)	80.77 (27.77)	58.65 (33.22)	t=1.63 p=0.13	-0.8	Mild improvement: 0 Moderate improvement: 3 Mild decline: 0 Moderate decline: 9
Role-emotion	82.9 (31.8)	87.18 (25.37)	69.23 (35.42)	t=1.69 p=0.12	-0.71	Mild improvement: 0 Moderate improvement: 2 Mild decline: 0 Moderate decline: 5
Mental health	73.8 (17.2)	73.08 (21.46)	73.08 (20.06)	t=0 p=1.0	0	Mild improvement: 3 Moderate improvement: 4 Mild decline: 1 Moderate decline: 2

Table 8: Details of donors who experienced clinically and socially relevant improvements in health related quality of life following donation

Scale	Donor 1	Donor 2	Donor 3	Donor 4	Donor 5	Donor 6	Donor 7	Donor 8
Physical functioning					Moderate			
Role-physical			Moderate					
Bodily pain			Moderate			Moderate		
General health					Mild	Moderate		
Vitality		Moderate	Moderate					
Social functioning			Moderate		Moderate	Moderate		
Role-emotion		Moderate	Moderate					
Mental health	Moderate		Moderate	Mild	Moderate	Moderate	Mild	Mild

Mild indicates a mild socially and clinically relevant improvement in SF-36 domain scores
Moderate indicates a moderately socially and clinically relevant improvement in SF-36 domain scores

Table 9: Correlation between preoperative and postoperative scores on the HADS and SF-36.

	Postoperative SF-36 scores		**Post operative HADS scores**	
	MCS	**PCS**	**Anxiety**	**Depression**
Preoperative MCS	r=0.25 p=0.4	r=-0.43 p=0.15	r=-0.48 p=0.13	r=-0.2 p=0.53
Preoperative PCS	r=-0.27 p=0.37	r=0.041 p=0.9	r=0.2 p=0.52	r=0.3 p=0.32
Preoperative HADS anxiety score	r=-0.35 p=0.25	r=-0.03 p=0.9	r=0.49 p=0.09	r=0.26 p=0.4
Preoperative HADS depression score	r=-0.43 p=0.14	r=0.16 p=0.6	**r=0.55** **p=0.05**	r=0.5 p=0.085

Table 10: Correlation between coping style and pre- and postoperative scores on the SF-36 and HADS

	Preoperative SF-36 scores		Postoperative SF-36 scores		preoperative HADS scores		Post operative HADS scores	
	MCS	**PCS**	**MCS**	**PCS**	**Anxiety**	**Depression**	**Anxiety**	**Depression**
Active coping	r=0.61 p=0.04	r=-0.9 p=0.79	**r=0.7** **p=0.01**	r=0.23 p=0.38	r=0.54 p=0.7	r=-0.63 p=0.03	r=-0.56 p=0.06	r=-0.55 p=0.06
Planning	r=0.05 p=0.89	r=0.09 p=0.77	r=0.63 p=0.03	r=0.59 p=0.04	r=-0.16 p=0.63	r=-0.3 p=0.35	r=-0.34 p=0.27	r=-0.41 p=0.19
Seeking instrumental social support	r=0.32 p=0.31	**r=-0.68** **p=0.01**	r=0.67 p=0.02	r=0.21 p=0.51	r=-0.4 p=0.2	r=-0.47 p=0.13	r=-0.61 p=0.04	r=-0.54 p=0.72
Seeking emotional support	r=0.9 p=0.79	r=-0.48 p=0.12	r=0.48 p=0.15	r=-0.1 p=0.75	r=0.09 p=0.79	r=-0.14 p=0.66	r=-0.53 p=0.79	r=-0.51 p=0.09
Suppression of competing activities	r=0.46 p=0.18	r=-0.09 p=0.78	r=0.012 p=0.97	r=0.1 p=0.77	r=-0.42 p=0.16	r=-0.29 p=0.36	r=0.21 p=0.52	r=0.16 p=0.61
Turning to religion	r=0.05 p=0.87	r=-0.22 p=0.49	r=0.5 p=0.10	r=0.51 p=0.09	r=-0.31 p=0.33	r=-0.17 p=0.60	r=-0.34 p=0.28	r=-0.29 p=0.37
Positive reinterpretation and growth	r=33 p=0.3	r=-0.45 p=0.14	r=0.31 p=0.33	r=0.27 p=0.39	r=-0.39 p=0.21	r=-0.17 p=0.60	r=-0.11 p=0.73	r=-0.9 p=0.78
Restraint coping	r=0.13 p=0.7	r=-0.23 p=0.5	r=0.22 p=0.5	r=0.19 p=0.55	r=-0.42 p=0.9	r=0.12 p=0.7	r=-0.21 p=0.51	r=-0.19 p=0.55
Acceptance	r=-0.24 p=0.46	r=0.8 p=0.81	r=0.3 p=0.35	r=0.56 p=0.06	r=0.93 p=0.77	r=0.19 p=0.56	r=-0.29 p=0.36	r=-0.48 p=0.12
Focus on and venting of emotions	r=-0.25 p=0.44	r=-0.05 p=0.90	r=-0.35 p=0.27	r=-0.26 p=0.41	r=0.61 p=0.37	r=0.56 p=0.06	r=0.31 p=0.34	r=0.44 p=0.15
Denial	r=-0.59 p=0.04	r=0.24 p=0.44	r=-0.35 p=0.27	r=0.7 p=0.82	**r=0.7** **p=0.01**	**r=0.89** **p=0.00**	r=0.47 p=0.13	r=0.46 p=0.13
Mental disengagement	r-0.2 p=0.9	r=-0.51 p=0.09	r=-0.56 p=0.06	r=-0.51 p=0.09	r=0.29 p=0.36	r=0.41 p=0.19	r=0.42 p=0.17	r=0.44 p=0.15
Behavioural disengagement	r=-0.21 p=0.52	r=0.01 p=1.0	r=-0.34 p=0.29	r=-0.28 p=0.38	r=0.37 p=0.23	r=0.56 p=0.06	r=0.13 p=0.69	r=0.35 p=0.26
Alcohol and drug use	r=0.19 p=0.57	r=-0.46 p=0.13	r=0.02 p=0.96	r=-0.22 p=0.49	r=0.25 p=0.94	r=-0.16 p=0.62	r=0.88 p=0.79	r=-0.21 p=0.51
humour	r=0.7 p=0.02	r=-0.11 p=0.75	r=0.06 p=0.86	r=-0.31 p=0.4	r=-0.62 p=0.04	r=-0.43 p=0.19	r=-0.59 p=0.86	r=0.45 p=0.9

Table 11: Correlation between donor decision making and preoperative and postoperative scores on the HADS and SF-36

	Preoperative SF-36 scores		Postoperative SF-36 scores		Preoperative HADS scores		Post operative HADS scores	
	MCS	**PCS**	**MCS**	**PCS**	**Anxiety**	**Depression**	**Anxiety**	**Depression**
Pressure to donate by transplant team[1]	r=0.22 p=0.47	r=0.19 p=0.53	r=0.16 p=0.6	r=0.13 p=0.68	r=-0.8 p=0.79	r=-0.56 p=0.86	r=0.007 p=0.98	r=-0.16 p=0.59
Pressure to donate by the recipient [1]	r=0.15 p=0.62	r=0.19 p=0.53	r=0.23 p=0.45	r=0.16 p=0.61	r=-0.06 p=0.84	r=-0.09 p=0.76	r=-0.13 p=0.67	r=-0.27 p=0.37
Pressure to donate by friends and family[1]	r=0.15 p=0.52	r=0.19 p=0.53	r=0.23 p=0.45	r=0.16 p=0.6	r=-0.06 p=0.83	r=-0.09 p=0.76	r=0.13 p=0.67	r=-0.27 p=0.37
Level of support from the individual involved in decision to donate[2]	r=-0.18 p=0.56	r=-0.12 p=0.69	r=0.29 p=0.34	r=0.26 p=0.38	r=0.13 p=0.67	r=0.005 p=0.99	r=-0.49 p=0.09	r=0.22 p=0.47

[1]scored on a 6point likert scores from strongly disagree to strongly agree [2]scored on a 10 point likert scale from not at all supportive to very supportive

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Appendix 2: Quality criteria data collection sheet

Study identification number: (*Include author, title, year of publication, journal title, pages*)		
Author(s):		
Title:		
Journal reference:		
Checklist completed by:		
Section 1: Study Rationale		
1.1	The study addresses an appropriate and clearly focused question.	1 Yes 0 No
1.2	The main objective of the study is clearly defined	1 Yes 0 No
Total score for section 1		/2
Section 2: Selection of Subjects		
2.1	The sample is representative of the population being studies.	1 Yes 0 No
2.2	The study reports the sample size.	1 Yes 0 No
2.3	The study indicates how many of the people asked to take part did so	1 Yes 0 No
2.4	The study reports the retention rate for each stage of follow up	1 Yes 0 No
2.5	Comparison is made between full participants and those lost to follow up.	1 Yes 0 No
2.6	The study states the inclusion and exclusion criteria.	1 Yes 0 No
Total score for section 2		**/6**
Section 3: Assessment		
3.1	The outcomes are clearly defined.	1 Yes 0 No
3.2	The measure of assessment of outcome is stated and is reliable and valid	2 well covered 1 adequately addressed 0 No, poorly addressed

Score for section 3		**/3**
Section 4: Confounding		
3.1	The main potential confounders are identified and taken into account in the design and analysis.	2 well covered 1 adequately covered 0 No, poorly addressed
Score for section 4:		**/2**
Section 5: Statistical analysis		
4.1	The statistical analysis is appropriate given the study design and the outcome measures used	1 Yes 0 No
4.2	Are effect sizes, confidence interval and p-values been reported where appropriate reported	1 Yes 0 No
Score for section 5		**/2**
Section 2: Overall assessment of the study		
Overall Total: / Percentage: % Quality rating: (Poor = <50%; Moderate=50-74%; Good= >75%)		

APPENDIX 3: QUESTIONNAIRE BOOKLET

NHS
Greater Glasgow and Clyde

UNIVERSITY of GLASGOW

PARTICIPANT INFORMATION SHEET

1. Introduction

My name is Yvonne McNeill and I am a student undertaking a Doctorate in Clinical Psychology at the University of Glasgow. As part of my course I must carry out a piece of research. I have chosen to carry a research project investigating how individuals decide to donate a kidney and what are the physical and psychological outcomes for individuals who donate a kidney.

I would like to invite you to take part in this research study. This is a new research study and is not related to anything that you may have taken part in before. Before you decide if you would like to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. If you have any questions or would like more information, please do not hesitate to talk your transplant coordinator. Take time to decide whether or not you wish to take part.

2. What is the purpose of the study?

Recent changes in the law have greatly increased the number of potential kidney donors. Donating a kidney, or any major organ, is obviously an important and potentially life-changing decision. It is essential that individuals who wish to donate are able to make an informed decision. In other words, that they are aware of the physical and emotional risks involved in donating a kidney.

We are interested in investigating how people decide to donate a kidney. For example, it would be interesting to learn if people make the decision independently or through discussion with family members. Would those who have donated still donate if they could decide again? Also, how could donor education and care during the recovery period be improved? We are also interested in whether the coping strategies people use to deal with difficult or stressful events help during the recovery period.

The study hopes to gather such information to help improve the quality of our service and minimise the risk of any difficulties donors may experience following donation.

3. Why have I been invited?

Your transplant coordinator is inviting all individuals who are donating a kidney at this hospital to provide information that may help answer the questions above. This information will then be used to educate future donors on the positive and negative aspects of donating a kidney.

4. Do I have to take part?

Taking part in the research is entirely voluntary; it is up to you to decide. Please read this information sheet carefully before making your decision. If you decide you would like to participate, we will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive at any time in the future.

5. What will I have to do?

If you decide to participate in this study you will be asked to complete the enclosed questionnaire booklet. We anticipate this will take no longer than 30 minutes and likely considerably less time than this. Once complete, we would ask you to return the completed questionnaire, alongside the completed consent forms in the stamp addressed envelope provided. Three months after your operation we will mail you a second set of questionnaire and a stamped addressed envelope for return. This will allow us to compare your health before and after your operation.

6. Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential. Any questionnaires you complete will not include your name and address so that you cannot be recognised. We will ask you to complete a demographics sheet which asks for your name and address as this will be used to identify who has completed questionnaires and also match up both sets of questions. However, once we receive this we will allocate you a number and will separate any identifiable information from your questionnaires.

7. What if there is a problem

If you have a concern about any aspect of this study, you should ask to speak to your transplant coordinator who will do their best to answer your questions. **Please contact:**

Name of transplant coordinator and phone number

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

8. What will happen to the results of the research study?

Hopefully the study will produce some interesting results. We would like to make these results available to participants and plan to send all participants a feedback letter highlighting the main findings. It may be possible to publish the findings of the study in a scientific journal. No participants will be identified in any report or publication.

9. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your

safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by The West of Scotland Research Ethics Service.

10. Further information and contact details

Information about the research project:

Name:	Transplant coordinator	Telephone

NHS
Greater Glasgow and Clyde

UNIVERSITY of GLASGOW

CONSENT FORM

Title of Project: Kidney donor decision making and psychosocial outcomes

		Please initial box:
1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected	☐
3	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records	☐
4	I agree to take part in the above study	☐

Name of patient (please print)	Date	Signature

Name of transplant coordinator	Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 to be kept in medical notes

NHS
Greater Glasgow and Clyde

UNIVERSITY *of* GLASGOW

Name:

Address

1. What is your gender?

Male ☐ 1 Female ☐ 2

2. What is your date of birth?

D	D	/	M	M	/	Y	Y

3. In relation to you, the person you will be donating your kidney to is:

Spouse ☐ 1 Son/ daughter ☐ 2 Parent ☐ 3 Sibling ☐ 4 Friend ☐ 5

Other relative ☐ 6 Please specify: _____ Other ☐ 7 Please specify: _____

4. Please indicate your martial status.

Married ☐ 1 Co-habiting ☐ 3 Divorced ☐ 5

Single ☐ 2 Single ☐ 4 Widowed ☐ 6

PLEASE TURN OVER

5. What is your ethnic origin? (Select one)

White	*Mixed*	*Asian, Asian Scottish or Asian British*	*Black, Black Scottish or Black British*	*Other ethnic background*
Scottish ☐ 1	Any Mixed background ☐ 5	Indian ☐ 6	Caribbean ☐ 11	Any other background ☐ 14
Other British ☐ 2	Please state: _____	Pakistani ☐ 7	African ☐ 12	Please state: _____
Irish ☐ 3		Bangladeshi ☐ 8	Any other Black ☐ 13.	
Any other White ☐ 4		Chinese ☐ 9	Please state: _____	
Please state: _____		Any other Asian ☐ 10		
		Please state: _____		

6. Please describe your employment status. (Select one)

Full-time employment	☐ 1	In higher education	☐ 4	Unemployed no benefits	☐ 7
Part-time employment	☐ 2	In further education	☐ 5	Unemployed on benefits	☐ 8
Retired	☐ 3	In a government training scheme	☐ 6	Other (e.g., housewife, carer)	☐ 9

Hospital Anxiety and Depression Scale (HADS)

nferNelson
understanding potential

Name: _____ Date: _____

FOLD HERE

Clinicians are aware that emotions pay an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

A D

I feel tense or 'wound up'
- [3] Most of the time
- [2] A lot of the time
- [1] From time to time, occasionally
- [0] Not at all

I still enjoy the things I used to enjoy
- [0] Definitely as much
- [1] Not quite so much
- [2] Only a little
- [3] Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
- [3] Very definitely and quite badly
- [2] Yes, but not too badly
- [1] A little, but it doesn't worry me
- [0] Not at all

I can laugh and see the funny side of things
- [0] As much as I always could
- [1] Not quite so much now
- [2] Definitely not so much now
- [3] Not at all

Worrying thoughts go through my mind
- [3] A great deal of the time
- [2] A lot of the time
- [1] Not too often
- [0] Very little

I feel cheerful
- [3] Never
- [2] Not often
- [1] Sometimes
- [0] Most of the time

I can sit at ease and feel relaxed
- [0] Definitely
- [1] Usually
- [2] Not often
- [3] Not at all

A D

I feel as if I am slowed down
- [3] Nearly all the time
- [2] Very often
- [1] Sometimes
- [0] Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach
- [0] Not at all
- [1] Occasionally
- [2] Quite often
- [3] Very often

I have lost interest in my appearance
- [3] Definitely
- [2] I don't take as much care as I should
- [1] I may not take quite as much care
- [0] I take just as much care as ever

I feel restless as if I have to be on the move
- [3] Very much indeed
- [2] Quite a lot
- [1] Not very much
- [0] Not at all

I look forward with enjoyment to things
- [0] As much as I ever did
- [1] Rather less than I used to
- [2] Definitely less than I used to
- [3] Hardly at all

I get sudden feelings of panic
- [3] Very often indeed
- [2] Quite often
- [1] Not very often
- [0] Not at all

I can enjoy a good book or radio or television programme
- [0] Often
- [1] Sometimes
- [2] Not often
- [3] Very seldom

Now check that you have answered all the questions

A D

TOTAL [ ] [ ]

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NHS
Greater Glasgow and Clyde

UNIVERSITY of GLASGOW

Please select the choice that best represents your response

1. Was there a family member/friend whom you involved in the decision to be a kidney donor?

Yes ☐ 1 No ☐ 2

2. In relation to you, this person is your:

Spouse ☐ 1 Son/ daughter ☐ 2 Parent ☐ 3 Sibling ☐ 4 Friend ☐ 5

Other relative ☐ 6 Please specify: _____ Other ☐ 7 Please specify: _____

3. Please select one of the six choices below that best represents how you made the decision about whether you would be an organ donor (*tick one*).

I made the decision about being an organ donor by myself ☐ 1

I made the decision about being an organ donor after seriously considering my family member/friend's opinions ☐ 2

My family member/friend and I shared responsibility for the decision about me being an organ donor ☐ 3

My family member/friend made the decision for me to be a donor after seriously considering my opinion ☐ 4

My family member/friend made the decision for me to be a donor ☐ 5

Other, please specify: _____ ☐ 6

_____

4. **If there was someone you involved in your decision to be a kidney donor, to what extent was this person supportive of your decision to donate?**

1--------2--------3--------4--------5--------6--------7--------8--------9--------10

Not at all supportive

Very supportive

COPE

Name:.....

Date:..... **Record Number:**.....

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.
Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU – not what you think 'most people' would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1. I try to grow as a person as a result of the experience. ☐
2. I turn to work or other substitute activities to take my mind off things. ☐
3. I get upset and let my emotions out. ☐
4. I try to get advice from someone about what to do. ☐
5. I concentrate my efforts on doing something about it. ☐
6. I say to myself "this isn't real". ☐
7. I put my trust in God. ☐
8. I laugh about the situation. ☐
9. I admit to myself that I can't deal with it, and give up trying. ☐
10. I restrain myself from doing anything too quickly. ☐

11. I discuss my feelings with someone. ☐
12. I use alcohol or drugs to make myself feel better. ☐
13. I get used to the idea that it happened. ☐
14. I talk to someone to find out more about the situation. ☐
15. I keep myself from getting distracted by other thoughts or activities. ☐
16. I daydream about things other than this. ☐
17. I get upset, and am really aware of it. ☐
18. I seek God's help. ☐
19. I make a plan of action. ☐
20. I make jokes about it. ☐

21. I accept that this has happened and that it can't be changed. ☐
22. I hold off doing anything about it until the situation permits. ☐
23. I try to get emotional support from friends and relatives. ☐
24. I just give up trying to reach my goal. ☐
25. I take additional action to try to get rid of the problem. ☐
26. I try to lose myself for a while by drinking alcohol or taking drugs. ☐
27. I refuse to believe that it has happened. ☐
28. I let my feelings out. ☐
29. I try to see it in a different light, to make it seem more positive. ☐
30. I talk to someone who could do something concrete about the problem. ☐

31. I sleep more than usual. ☐
32. I try to come up with a strategy about what to do. ☐
33. I focus on dealing with this problem and, if necessary, let other things slide a little. ☐
34. I get sympathy and understanding from someone. ☐
35. I drink alcohol or take drugs, in order to think about it less. ☐
36. I kid around about it. ☐
37. I give up the attempt to get what I want. ☐
38. I look for something good in what is happening. ☐
39. I think about how I might best handle the problem. ☐
40. I pretend that it hasn't really happened. ☐

41. I make sure not to make matters worse by acting too soon. ☐
42. I try hard to prevent other things from interfering with my efforts at dealing with this. ☐
43. I go to the cinema or watch television, to think about it less. ☐
44. I accept the reality of the fact that it happened. ☐
45. I ask people who have had similar experiences what they did. ☐
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot. ☐
47. I take direct action to get around the problem. ☐
48. I try to find comfort in my religion. ☐
49. I force myself to wait for the right time to do something. ☐
50. I make fun of the situation. ☐

51. I reduce the amount of effort I'm putting into solving the problem. ☐
52. I talk to someone about how I feel. ☐
53. I use alcohol or drugs to help me get through it. ☐
54. I learn to live with it. ☐
55. I put aside other activities in order to concentrate on this. ☐
56. I think hard about what steps to take. ☐
57. I act as though it hasn't even happened. ☐
58. I do what has to be done, one step at a time. ☐
59. I learn something from the experience. ☐
60. I pray more than usual. ☐

SF-36 v2™ Health Survey

(SF-36 v2 Standard, US Version 2.0)

To be completed by the PATIENT

Name (Last, First, Middle Initial)
Identification Number
Event

Directions: *Answer every question by filling in the correct circle or writing in the information. If you need to change an answer, completely erase the incorrect mark and fill in the correct circle. If you are unsure about how to answer a question, please give the best answer you can.* **Mark only one answer for each question unless instructed otherwise.**

Today's Date (MM/DD/YY)
☐☐ / ☐☐ / ☐☐

Shade circles like this: ●
Not like this: ⊗ ✓

Mark only one answer for each question. Please do not mark outside the circles or make stray marks on the questionnaire.

01. **In general, would you say your health is:**

○ Excellent ○ Very Good ○ Good ○ Fair ○ Poor

02. **Compared to one year ago, how would you rate your health in general now?**

○ Much better ○ Somewhat better ○ About the same ○ Somewhat worse ○ Much worse

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	Yes, limited a lot	Yes, limited a little	No, not limited at all
03. **Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports**	○	○	○
04. **Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf**	○	○	○
05. **Lifting or carrying groceries**	○	○	○
06. **Climbing several flights of stairs**	○	○	○
07. **Climbing one flight of stairs**	○	○	○
08. **Bending, kneeling, or stooping**	○	○	○
09. **Walking more than a mile**	○	○	○
10. **Walking several hundred yards**	○	○	○
11. **Walking one hundred yards**	○	○	○
12. **Bathing or dressing yourself**	○	○	○

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	All of the time	Most of the time	Some of the time	A little of the time	None of the time
13. **Cut down on the amount of time you spent on work or other activities**	○	○	○	○	○
14. **Accomplished less than you would like**	○	○	○	○	○
15. **Were limited in the kind of work or other activities**	○	○	○	○	○
16. **Had difficulty performing the work or other activities (for example, it took extra effort)**	○	○	○	○	○

Please continue on next page

52852

14 - ☐

Patient Last Name: _____

During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	All of the time	Most of the time	Some of the time	A little of the time	None of the time
17. **Cut down the amount of time you spent on work or other activities**	○	○	○	○	○
18. **Accomplished less than you would like**	○	○	○	○	○
19. **Did work or activities less carefully than usual**	○	○	○	○	○

20. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?**

○ Not at all ○ Slightly ○ Moderately ○ Quite a bit ○ Extremely

21. **How much bodily pain have you had during the past 4 weeks?**

○ None ○ Very mild ○ Mild ○ Moderate ○ Severe ○ Very severe

22. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

○ Not at all ○ A little bit ○ Moderately ○ Quite a bit ○ Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
23. **Did you feel full of life?**	○	○	○	○	○
24. **Have you been very nervous?**	○	○	○	○	○
25. **Have you felt so down in the dumps that nothing could cheer you up?**	○	○	○	○	○
26. **Have you felt calm and peaceful?**	○	○	○	○	○
27. **Did you have a lot of energy?**	○	○	○	○	○
28. **Have you felt downhearted and depressed?**	○	○	○	○	○
29. **Did you feel worn out?**	○	○	○	○	○
30. **Have you been happy?**	○	○	○	○	○
31. **Did you feel tired?**	○	○	○	○	○
32. **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**	○	○	○	○	○

How TRUE or FALSE is each of the following statements for you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. **I seem to get sick a little easier than other people**	○	○	○	○	○
34. **I am as healthy as anybody I know**	○	○	○	○	○
35. **I expect my health to get worse**	○	○	○	○	○
36. **My health is excellent**	○	○	○	○	○

52852

14 - _____

NHS
Greater Glasgow and Clyde

UNIVERSITY of GLASGOW

LIVING DONOR SURVEY

Your answers to these questions will be strictly confidential. Please answer all the questions as honestly as possible. We hope to use this information to improve the living donation process. Please circle the answers that apply to you. In questions where there are multiple choices, circle the answer that best represents your response. We are interested in your experience so, there are no wrong answers. You are encouraged to add any additional comments.

1. The next set of questions asks about the information that you received before your donation surgery

1.1 The process for evaluating me as a kidney donor was explained to me:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

very vaguely | moderately vaguely | somewhat vaguely | somewhat clearly | moderately clearly | very clearly

1.2 The information that I received about the actual surgery was:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

very vague | moderately vague | somewhat vague | somewhat clear | moderately clear | very clear

1.3 Prior to surgery I was told of all the possible complications:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

very vaguely | moderately vaguely | somewhat vaguely | somewhat clearly | moderately clearly | very clearly

1.4 The information I received about the risk of death was:

1----------2----------3----------4----------5----------6

very vague | moderately vague | somewhat vague | somewhat clear | moderately clear | very clear

1.5 Before proceeding with surgery my questions were:

1----------2----------3----------4----------5----------6

completely ignored | moderately ignored | somewhat ignored | somewhat answered | moderately answered | completely answered

1.6 The information I received about the recovery process was:

1----------2----------3----------4----------5----------6

very vague | moderately vague | somewhat vague | somewhat clear | moderately clear | very clear

2 The next set of questions asks about your experience around the time of surgery

2.1 Compared to what I expected, the pain of my surgery was:

1----------2----------3----------4----------5

much more | more | as expected | less | much less

2.2 Compared to before donation, my physical appearance is now:

1----------2----------3----------4----------5

much worse | worse | as expected | better | much better

2.3 Compared to what I expected, my surgical scar is:

1----------2----------3----------4----------5

much worse | worse | as expected | better | much better

2.4 When I expressed needs or complaints while in the hospital, the transplant team:

1	2	3	4	5	6
completely ignored	moderately ignored	somewhat ignored	somewhat answered	moderately answered	completely answered

2.5 Compared to what I expected, I was in the hospital:

1	2	3	4	5
many more days	more days	as many days as expected	fewer days	many fewer days

2.6 Number of days I was in the hospital: _____

2.7 I had a complication immediately following surgery (tick one):

Yes ☐ 1 No ☐ 2

2.8 If yes, what? _____

2.9 How long did it last? _____ days

2.10 Overall my care was:

1	2	3	4	5	6
very bad	moderately bad	somewhat bad	somewhat good	moderately good	excellent

3. The next set of questions asks about your experiences after going home from your donation surgery

3.1 When I expressed needs or complaints after going home from the hospital the transplant team _____ me.

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

completely ignored	moderately ignored	somewhat ignored	somewhat addressed	moderately addressed	completely addressed

3.2 I was able to return to my pre-donation occupation with the same employer (tick one):

Yes ☐ 1 No ☐ 2

3.3 I had a complication from the surgery after going home from the hospital (tick one):

Yes ☐ 1 No ☐ 2

3.4 If yes, what?

_____

3.5 How long did your complication after surgery last? _____ days

3.6 I was readmitted to the hospital for reasons related to the donation process (tick one):

Yes ☐ 1 No ☐ 2

3.7 If yes, how many times were you readmitted?

_____

3.8 Current occupation and employer:

_____

_____

_____

3.9 If you were not able to return to your pre-donation occupation with the same employer, do you feel this is a result of the surgery? (tick one):

Yes ☐ 1 No ☐ 2

4. For the next set of questions: When compared to before donation

4.1 The hours I currently work are:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

many fewer fewer the same more many more

4.2 My current level of social activity is:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

much lower lower the same higher much higher

4.3 My current level of physical activity is:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

much lower lower the same higher much higher

4.4 My mood or emotions are:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

much worse worse the same better much better

4.5 My level of sexual activity is:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

greatly decreased decreased the same increased greatly increased

4.6 Compared to what I expected, the time it took for me to completely recover was:

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5

much more | more | as expected | less | much less

4.7 How would you rate your recovery since the surgery?

1 ---------- 2 ---------- 3

not at all recovered | somewhat recovered | completely recovered

5. The next set of questions asks about your feelings regarding living kidney donation

5.1 The use of living kidney donation should increase

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

strongly disagree | moderately disagree | somewhat disagree | somewhat agree | moderately agree | strongly agree

5.2 Living kidney donation should be a routine option in the treatment of kidney disease

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

strongly disagree | moderately disagree | somewhat disagree | somewhat agree | moderately agree | strongly agree

5.3 To someone thinking about donating his or her kidney, I would

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

strongly discourage it | moderately discourage it | somewhat discourage it | somewhat encourage it | moderately encourage it | strongly encourage it

5.4 Knowing what I know now, I would donate again

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6

strongly disagree | moderately disagree | somewhat disagree | somewhat agree | moderately agree | strongly agree

5.5 If you did not donate your kidney, the person who received your kidney would have received a kidney donated from a person who died

1----------2----------3----------4----------5----------6

strongly disagree	moderately disagree	somewhat disagree	somewhat agree	moderately agree	strongly agree

5.6 If you did not donate your kidney, the person who received your kidney would have been kept alive with dialysis

1----------2----------3----------4----------5----------6

strongly disagree	moderately disagree	somewhat disagree	somewhat agree	moderately agree	strongly agree

6. The next set of questions asks whether you felt any pressure to donate

6.1 At times I felt pressured to donate by the transplant team

1----------2----------3----------4----------5----------6

strongly disagree	moderately disagree	somewhat disagree	somewhat agree	moderately agree	strongly agree

6.2 At times I felt pressured to donate by the person who received my kidney

1----------2----------3----------4----------5----------6

strongly disagree	moderately disagree	somewhat disagree	somewhat agree	moderately agree	strongly agree

6.3 At times I felt pressured to donate by my friends or family

1----------2----------3----------4----------5----------6

strongly disagree	moderately disagree	somewhat disagree	somewhat agree	moderately agree	strongly agree

7. The next two questions are about the extent to which you and the person who received your kidney have benefited from the donation.

7.1 What is the health at this time of the person who received your kidney?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

very sick very healthy

7.2 To what extent have you benefited from kidney donation surgery (may include psychological or spiritual benefit)

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

no benefit great deal of benefit

8. The next 6 questions are for menstruating women only

8.1 I have notice a change in menstruation (tick one):

Yes ☐ 1 No ☐ 2

8.2 If yes, what?

_____

8.3 I plan to have children in the future (tick one):

Yes ☐ 1 No ☐ 2

8.4 I have been trying to get pregnant (tick one):

Yes ☐ 1 No ☐ 2

8.5 I currently use birth control (tick one):

Yes ☐ 1 No ☐ 2

8.6 I have become pregnant since my surgery (tick one):

Yes ☐ 1 No ☐ 2

9. Final questions

9.1 If you have taken time off work, how many weeks since your surgery have you taken off?

_____ weeks

9.2 If you have taken time off work, how many weeks have been paid sick leave?

_____ weeks

9.3 Have you seen your primary care provider (e.g., GP or practice nurse) since your donation? (tick one):

Yes ☐ 1 No ☐ 2

9.4 If yes, how soon after donating did you see your primary care provider?

_____ weeks

9.5 Reason for seeing your primary care provider since your donation hospitalisation?

1----------2----------3----------4----------5

Not applicable, I have not seen my GP	Non-kidney related problem	Kidney related health problem	Just to check on the health of my kidney	Just to check on my general health

9.6 Does your primary care provider want to see you more frequently since your donation? (tick one):

Yes ☐ 1 No ☐ 2

9.7 Has your primary care provider communicated with the surgical team who performed your surgery?

Yes ☐ 1 No ☐ 2 Don't know ☐ 3

9.8 Do you feel your primary care provider is experienced enough to care for you with regard to your donation?

Yes ☐ 1 No ☐ 2 Don't know ☐ 3

9.9 Do you have any other concerns regarding your primary care provider and your donation?

9.10 Do you have any comments or suggestions to help improve the donation process?

9.11 Is there any other information that you wish you had received prior to your donation?

Appendix 4: Major Research Proposal: the study of living kidney donor decision-making and psychosocial outcomes

INTRODUCTION

It is widely accepted that renal transplantation from a live donor poses the best outcome for individuals with end stage renal failure (ESRF) as the survival rate is higher and the kidney has a longer life span (Gjertson, 2003). However, research examining the impact kidney donation has on the donor is limited. Research to date concurs that kidney donors do not experience any long-term medical complications following donation; the life expectancy of donors is similar to that of non-donors and the risk of ESRF does not increase (Ibrahim *et al.*, 2009). With respect to psychological health, initially the available literature concluded that live kidney donors have a highly positive experience with kidney donation and an enhanced self-esteem and self-regard related to this act. This conclusion was drawn from several studies reporting that donors' post-operative psychosocial outcome scores on the Medical Outcome Study 36-item Short Form Health Survey (SF-36) indicated a higher or comparable quality of life to aged matched controls (Buell *et al.*, 2005; Chen *et al.*, 2004; Fehrman- Ekholm *et al.*, 2000; Giessing *et al.*, 2004; Johnson *et al.*, 1999; Perry *et al.*, 2003). However, more recently it has been argued that living kidney donors are a select sample of healthy individuals and therefore pre-donation their SF-36 scores are inflated in comparison to the general population (Walton-Moss *et al*., 2007). Thus it is possible that donation impacts negatively on donors' psychosocial health yet their SF-36 scores will still be comparable with population norms. Therefore, in order to give an accurate description of the pace of recovery following donation and the psychosocial outcome of donation, a prospective study design in which the SF-36 scores are compared pre- and post- operatively is required.

Data from prospective studies suggests that for the majority, kidney donation does not have a long-term clinical impact on physical and psychological health of donors. For example, Wolf et al (2001) and Taghavi et al (2001) reported that donors' pre- and post-operative scores on the SF-36

and the SCL-90 were similar. Virzi et al (2007) reported a significant improvement in all SF-36 scores with the exception of physical activities. Lumsdaine et al (2005) reported that donors' physical and psychological domain scores on the world health organization quality of life questionnaire showed a marked decrease 6 weeks after donation. However, the authors concluded that living kidney donation did not have any long-term detrimental effect on the physical or psychological well being of donors. This was mainly due to the finding that 12-month postoperative scores were equal to that of pre-donation and at all times remained higher or comparable with population norms. Furthermore, there was no change in the donors' social or environmental domain scores and the donors and recipient experienced a significant improvement in their mutual relationship. By comparison, Smith et al (2004) reported a statistically significant decrease in the Mental Health Component Summary (MCS) score of the SF-36 with an effect size of –0.53 and –0.63 at 4 month and one year postoperative. However, this change was clinically significant for just 19% of the population. Whilst Smith et al (2004) found a statistically significant impact on the MCS score but not the Physical Health Component Summary (PCS) score, Bergman et al (2005) reported statistically significant changes in the PCS score but not the MCS score. However, once again, for the majority of the sample this was not clinically significant.

The impact of kidney donation on the psychiatric morbidity of donors remains unclear. Where Virzi et al (2007) reported a significant reduction on depression and anxiety scores, Minz et al (2005) reported a significant increase and Tanriverdi et al (2004) reported lower depression scores on the BDI but increased prevalence of anxiety following donation. By comparison, Smith et al (2004) reported that point prevalence of DSM-IV psychiatric caseness increased from 2% pre-donation to 25% and 15% four and 1year postoperative respectively.

Although for the majority, live kidney donation does not seem to have a long-term negative impact, a small proportion of donors have reported adverse psychosocial outcomes, regretted

donating, and described the experience as stressful (Fehrman- Ekholm *et al.*, 2000; Isotani *et al.*, 2002; Johnston *et al.*, 1999). Understanding the factors that lead to poorer psychosocial outcome after donation for some individuals will inform the psychological screening of potential donors and post-operative follow-up of donors. To date several factors that increase the risk of a poor psychosocial outcome have been identified. Individuals who feel ignored or abandoned after donation (Brown & Sussman, 1982; Schover *et al.,* 1997) or perceive poor recipient reciprocation (Minz *et al.*, 2005) are more likely to report poor psychosocial outcomes. Unsuccessful transplantation (Fisher *et al.*, 2005; Hivvas *et al.,* 1980; Isotani *et al.*, 2002 and Johnston *et al.*, 1999) in particular recipient death (Minz *et al.*, 2005 and Taghavi *et al.,* 2001) leads to poorer psychosocial outcome. Donors who perceive that their own health has been adversely affected by donation (Ozcurumez *et al.*, 2004) or who have experienced persistent pain or prolonged hospitalisation (Minz *et al.*, 2005) report poorer quality of life after donation. Others report that the donation process itself does not directly affect their quality of life after donation but rather the donation process aggravates environmental stressors such as feelings of being unsupported (Varma et al, 1992) or existing marital discord (Smith et al, 1986) which in turn affects their quality of life.

The stress experienced following medical procedures varies not only in accordance with the degree of intrusiveness, physical pain and discomfort but also in accordance with the perceived meaning of the procedure and the individuals coping style (Benyamini, 2007). As such, there is extensive evidence to suggest a relationship between coping style and outcomes relative to physical and psychological health (Beutler et al, 2003). Avoidant coping with the medical complaint, and the physical and psychological distress it causes, has been linked to negative outcomes such as increased pain in migraine suffers (Marlowe et al, 2003), poorer prognosis in cardiac patients (Kelsey & Leitten., 1996), increased relapse in psychiatric cohorts (Lemke & Moos, 2002 and 2003), increased risk of depression in the general population (Cronike &Moos,

1995), and poorer treatment outcome (Beutler *et al.*, 2003). By contrast, active coping has been linked with better outcomes in both adults (Rosenberger *et al.*, 2004) and adolescents (LaMontagne *et al.*, 2004). The impact of coping style on psychosocial outcome following live kidney donation has not been investigated. Identifying the link between coping style and psychosocial outcome following kidney donation is imperative to screening potential donors and post-operative counselling and thus represents an area where research is greatly needed.

AIMS AND HYPOTHESES

AIMS

- To investigate the post-operative quality of life of live kidney donors.
- To investigate which variables predict post-operative psychosocial outcome. To gather information regarding how individuals decide to become living kidney donors and how satisfied they are with their pre- and post-operative care.
- To investigate whether the donor decision-making process and satisfaction with the donation process is affected by the type of donor-recipient relationship.

HYPOTHESES

- The postoperative psychosocial health of live kidney donors will not differ significantly from their pre-operative psychosocial health.
- Coping style will mediate the relationship between the donor decision making process and quality of life after donation

PLAN OF INVESTIGATION

INCLUSION CRITERIA FOR PARTICIPANTS

This study aims to include:

Live kidney donors who undergo a nephrectomy[2] at Manchester Royal Infirmary, Western Infirmary Glasgow, St. James University Hospital, Leeds and Royal Infirmary of Edinburgh.

- Can read and write in English
- Are aged 18 years and above

RECRUITMENT PROCEDURE

Transplant coordinators are responsible for identifying a donor, providing support and education for the donor, all pre-donation assessments, for organising organ and tissue retrieval, ensuring transplantation runs smoothly and undertaking a post-operative assessment. Therefore, as they represent the hub of the transplant team and have the most frequent contact with the donor, recruitment will take place via the transplant coordinator. The recruitment procedure will be as follows:

- Transplant coordinators will make patient information sheets available to all prospective kidney donors who fulfil inclusion criteria for the present study.
- Prior to the nephrectomy[3], individuals who wish to participate will sign a consent form and be given the donor questionnaire booklet 1 and a SAE for return to the principle researcher (YMcN)
- The principle researcher will contact the renal unit to obtain an estimated date of transplantation.

[2] the removal of the kidney
[3] A discussion will take place with each site to decide at which appointment this will take place.

- Three months post-operation, the researcher will mail questionnaire booklet 2 and a SAE for return to the researcher.
- At the end of the study each participant and transplant coordinator will be informed of the study's findings.

MEASURES

Questionnaire booklet 1 (appendix 1) contains a patient information sheet, demographic form, consent form, a checklist and the following questionnaires:

- The Donor Decision Control Scale

The Donor Decision Control Scale is a three-item 5-point likert scale indicating the extent to which donors involve a family member(s) in their decision to donate. Level one is a decision made independently by the donor; level two is a decision made by the donor after consulting with a family member(s); level three is a shared decision made by both the donor and a family member(s); level four is the donor relying on a family member(s) to make the decision after consulting with the donor; level five is the donor relying on a family member(s) to make the decision that the donor will donate. The test-retest reliability for this scale in a prospective study of donor decision-making and outcomes was 0.76 (Walton-Moss *et al.*, 2007).

- The COPE

The COPE is a self-report multidimensional coping inventory, which assesses the different ways in which individuals respond to stress. It contains 13 conceptually distinct subscales. Five subscales measure problem-focused coping, where individuals actively try to alter the stressful situation. Five subscales measure emotion-focused coping, where an individuals' actions are directed at regulating the emotional response to the stressor. Three subscales measure other less useful, coping responses such as focusing on and venting of emotion, behavioural disengagement and mental disengagement.

The validity and reliability of the COPE has been tested by administering the COPE and several other personality questionnaires to 978 college students (Carver *et al.*, 1989). The concurrent validity test showed that the active coping and planning subscales on the COPE correlated significantly with scales of optimism, control, self-esteem, hardiness and Type A personality (r=0.20-0.32) and active coping was inversely correlated with trait anxiety (r=-0.25). With respect to reliability the internal consistency coefficients (cronbach's alpha) were 0.62-0.92. Test-retest reliability was tested with a further 89 students (eight-week retest) and 166 students (six-week retest) with correlations between 0.42 and 0.77. The correlation between the scale items was 0.02-0.69, however this can be interpreted as supporting the opinion that the subscales are empirically distinct domains (Bowling, 2005).

- The Medical Outcomes Study 36-item Short Form Health Survey (SF-36)

The SF-36 is a multipurpose[4] health survey measuring physical and mental health. The Physical Health Summary (PCS) is comprised from the following four domains, physical functioning, role-physical, bodily pain and general health. The Mental Health Summary (MCS) is comprised from the following four domains, vitality, social functioning, role-emotional, and mental health.

The results of the SF-36 can be presented as either two summary scores, the MCS score and the PCS score or as scores on each of the eight domains.

[4] The SF-36 is a generic measure and therefore does not target one specific age, disease or treatment group.

For a UK sample, Ware et al (1994) reported that the internal consistency reliability was 0.92 for the PCS and 0.89 for the MCS. The test-retest reliability for an interval of two weeks was 0.89 for the PCS and 0.80 for the MCS.

The SF-36 has rapidly become the generic health measure of choice and is widely used as a measure of broader health quality of life as it contain eight of the most frequently measured health concepts (Bowling, 2005). Within in the renal transplant literature, the Short Form Health Survey is the most frequently used patient reported measure of quality of life (Butt *et al.*, 2008), with 65% of the studies investigating the psychosocial outcome for live donors choosing this as their validated questionnaire and 73% of these relying on this alone to measure quality of life. Within these studies the SF-36 has been administered post operatively and the scores obtained compared to population norms or control groups. However, recently Walton-Moss et al (2007) administered the SF-36 before nephrectomy and found that donors scored as much as 20% higher than the US population. The authors recommend that studies need to compare donors health related quality of life before and after surgery to provide a more accurate report of psychosocial outcome.

- Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond and Snaith, 1983) is 14-item self-report measure designed to screen for the presence of mood disorders in medically ill patients. The concurrent validity of the scale was tested by comparing the results of a clinical assessment with the HADS scale results. This yielded significant correlations, 0.54 for anxiety and 0.79 for depression (Zigmond and Snaith, 1983). The scale has also been shown to be a valid measure of the severity of mood disorders and therefore the repeated administration of this scale at subsequent visits to the clinic will provide useful information concerning progress.

Questionnaire pack 2 (appendix 2) contains a checklist and the following questionnaires:

- The Living Donor Survey

The Living Donor Survey is designed to measure attitude toward living kidney donation, satisfaction with donation education, hospital care, care after discharge and health after surgery (Beavers *et al.*, 2001). In a study of donor decision-making and outcomes the internal consistency of the dimension that measured attitude to living donation was 0.75 using Cronbach's alpha (Walton-Moss *et al.*, 2007)

- The SF-36

As above.

- HADS

As above.

DESIGN

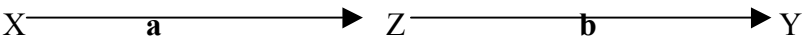
DATA ANALYSIS

A one tailed t-test will compare donors' pre- and post-operative SF-36

With respect to the HADS, individuals who score eight or less on either scale will be defined as having no significant anxiety or depression. Individuals who score between eight and eleven will be considered to be "doubtful cases." Individuals who score between eleven and twenty-one are considered to have anxiety or depression and will be termed "cases". A one tailed t-test will compare donors' pre- and post-operative HADS scores.

Mediation analysis will be conducted to assess whether the relationship between donor decision-making and psychosocial outcomes is mediated by the individuals coping style. Mediation is a hypothesized casual chain in which one variable affects a second variable that, in turn affects a third variable. The intervening variable, Z, is called the mediator as it mediates the relationship

between the predictor variables, X, and the outcome variables, Y. Mediation can be depicted in the following way:



Paths a and b are called a direct effect but the mediation effect in which X leads to Y through Z is called the indirect effect. This indirect effect represents the proportion of the relationship between X and Y that is mediated by Z.

To test whether coping style mediates the relationship between decision making and psychosocial outcome following donation, three regression analyses will be conducted on each dimension of the SF-36. The first regression will examine the relationship between the predictor (i.e. answers on the Donor Decision Control Scale) and the mediator (i.e. answers on the COPE). The second, between the predictor and dependent variable (i.e. SF-36 scores) and the final regression, both the predictor and mediator on the dependent variable. If mediation exists, the predictor should be significant in the first two regressions but not in the third (or significantly reduced, indicating partial mediation), whereas the mediator must be a significant predictor in the third regression

JUSTIFICATION OF SAMPLE SIZE

Participation rate

There are 16 published studies investigating the psychosocial outcomes for live kidney donors using a prospective design. Within these the percentage of eligible donors that agreed to participate in the study varies from 80% (Walton- Moss *et al.*, 2007) to 100% (Aguiar *et al.*, 2007; Minnee *et al.*, 2008; Nejatisafa *et al.*, 2008 and Sanner *et al.*, 2005). Therefore the estimated minimum participation rate is 80%.

Retention Rate

Of the 16 published studies, seven failed to report retention (Bergman et al, 2005; Kok et al, 2006; Minz et al, 2005; Simmons et al, 1982; Taghavi et al, 2001; Varma et al, 1992 and Yoo et al, 1996). The remaining studies and the reported retention rates are presented below. As can be seen the retention rates for three months post surgery vary from 64.5% to 100%. Therefore estimated minimum three month retention rate is 64.5%.

AUTHOR	*Time elapsed since nephrectomy*							
	1 week	**2 weeks**	**3 weeks**	**1 month**	**3 months**	**4 months**	**6 months**	**1 year**
Walton Moss et al (2007)					64.5%			
Wolf et al (2001)							60%	
Smith et al (2004)						94%		94%
Lumsdaine et al (2005)								82%
Minnee et al (2008)	100%	100%		100%	100%		100%	100%
Sanner et al (2005)			100%					
Virzi et al (2007)						100%		
Aguiar et al (2007)					90%			
Nejatisafa et al (2008)					84%		84%	

Statistical Power

Smith et al (2004) measured the psychosocial outcomes for live kidney donors 4- and 12-month postoperative using a prospective design. The effect size for the PCS score and the MCS score at four months was -0.35 and -0.63 respectively. Thus assuming the convention of $\alpha = 0.05$ and power of 0.8 the sample size required to detect a statistically significant difference between the baseline and three-month post operative PCS and MCS scores is 52 and 18 respectively.

For the 12-month follow-up, Smith et al (2004) reported the effect sizes for the domain scores. The effect sizes and the corresponding sample size required to detect a statistically significant difference, assuming power of 0.8 and at significance level 0.05 are presented below.

SF-36	*Effect size*	**Sample req.**
Physical functioning	0.22	130
Role physical	0.42	37
Bodily pain	0.4	41
General health	0.35	52
Vitality	0.69	15
Social functioning	0.58	20
Role emotion	0.82	11
Mental health	0.31	66

Recruitment

Data concerning the number of live kidney transplants carried out in the financial year of 1st April 2008 to 31st March 2009 is available from the UK Transplant Organisation (transplant activity report). The number of live kidney transplants carried out in Glasgow, Edinburgh, Leeds and Manchester within this period was 36, 20, 40 and 54respectively. Therefore basing recruitment on the figures for 2008-2009, 6 month recruitment period and participation would be as follows: 75 potential participants, 60 recruited (based on an 80% participation rate) and 3-month follow-up data available for 39 individuals (based on retention of 64.5%). Thus, the current study would have had enough power to detect a statistically significant difference in the MCS scores and the corresponding domains with the exception of the physical functioning, bodily pain and general health domains. With respect to the PCS score and the physical functioning, bodily pain and general health domains the study will have been able to report the number of individuals who

have a clinically significant difference as indicated by a difference of 10 or more points between the pre- and post operative score

SETTING AND EQUIPMENT

This study will not involve the use of equipment and it is not necessary to purchase the license for the questionnaires used in this study.

HEALTH AND SAFETY ISSUES

PARTICIPANT SAFETY ISSUES

The transplant coordinator, who monitors the health of the donor following transplant, will be notified of any individual identified as requiring medical or psychological care. They will then refer this individual to the appropriate psychological services attached to the renal unit. The proposed sites have been selected because each has dedicated psychological input.

The study will not screen for cognitive impairment or psychological morbidity but will rely on the screening processes of the renal unit. The study aims to measures the pre- and post-operative psychosocial health of donors at each site and therefore it is essential the study does not alter the donation process in any way.

If a participant has pre-operative psychological morbidity this will not affect the study outcomes, as analysis is focused on identifying postoperative changes in psychosocial health.

FINANCIAL ISSUES

A funding application has been made to the department of psychological medicine for the cost of two SAE envelopes per participant and the paper and photocopy costs of questionnaires. Travel costs to Manchester Royal Infirmary, Salford Royal Hospital and Royal Infirmary of Edinburgh have also been included. Each of the proposed sites have agreed in principal to participate but

have requested a meeting in person so that I can meet with each member of the renal transplant team, answer questions and together we can agree a site specific methodology. Salford Royal Hospital does not carry out live kidney transplants, all live kidney transplants take place at Manchester Royal Infirmary. However, Salford Royal Hospital employs live kidney donor co-ordinates to provide the pre- and post-operative care for those individuals who donate a kidney to a Salford Royal Hospital patient.

As detailed in the attached Research Equipment, Consumables and Expenses form, the estimated total cost for this study will be £402.92.

TIMETABLE

- July 2009: Submission of proposal to course
- August: writing shortened version of proposal
- August: Anticipate that feedback will be received by course.
- September and October: Applying for Ethics and R&D approval for Glasgow site.
- September and October: With respect to Edinburgh and Manchester initially contact site by phone to obtain correct email addresses and consent to forward proposal, email shortened proposal and cover letter explaining study to appropriate staff, follow-up by telephone
- November: start recruitment at Glasgow site.
- November: cut-off date for recruiting Edinburgh and Manchester sites, R&D and ethics applications for additional sites
- 1st April 2010: stop recruitment donors
- 1st July: final follow-up assessment
- July: write up.

PRACTICAL APPLICATION

Understanding the medical and psychological outcomes for donors is crucial to guiding informed consent and also to the development of services that maintain the long-term health of donors. Therefore, the Institute of Medicine and several transplant organizations including the American Society of Transplant Surgeons, The Division of Transplantation of the Health Resources and Services Administration, and the National Institutes of Health have recommended that transplant centres collect data on the medical and psychological outcomes of live donors which can be provided to future individuals considering donation (Adams *et al.*, 2002).

The outcomes of this study will guide education of potential donors, inform potential donors of the risks and benefits of donation therefore promoting informed consent, assist in the psychological assessment of potential donors and help identify appropriate care after donation.

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APPENDIX 5: PUBLICATION OF PILOT STUDY

Decision making and psychosocial outcomes among living kidney donors: a pilot study

With an increasing number of available kidney transplant donors comes greater demand for systematic screening of prospective donors to ensure the integrity of the donor's decision and to minimize the risk of a poor postoperative outcome. The present study was intended to explore psychosocial outcomes after kidney donation, aspects of donors' decision making, and donors' experience of the transplantation process. It was hoped that this pilot study would inform the design of a large-scale longitudinal prospective investigation of psychosocial outcomes of kidney donation. In this cross-sectional, retrospective investigation, all patients who had received psychosocial screening before their kidney donation were approached. Seventeen of 43 previous kidney donors responded to a postal questionnaire. Donors' health-related quality of life was higher than population norms on all dimensions. Most participants reported involving someone else in the decision-making process. Donors indicated high levels of satisfaction with virtually all aspects of the donation process. The generalizability of the findings in the context of the limitations of the present pilot study is discussed and specific suggestions for the design of future studies are provided. (*Progress in Transplantation.* 2010;20:53-57)

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Recent legislative changes[1] permitting consideration of kidneys from nonrelated donors have led to an increase in the number of living donor transplantations. With this change comes a greater need for the development of thorough screening procedures of prospective donors in order to promote fully informed consent and optimize the safety of donors. Donors' postoperative quality of life has been widely studied with a general, albeit tentative, consensus that donors' quality of life is at least equivalent, if not better than that of controls.[2] Beyond investigating health-related quality of life, little investigation of outcomes relating to psychosocial well-being has been done. Some concern about donors' well-being has been expressed,[3] with donors seemingly having an increased likelihood of developing psychological morbidity.[4] Such information regarding the true extent of risk is required for fully informed consent and the evaluation of prospective donors for the presence of risk factors.

The importance of donors' process of decision making is beginning to be recognized as a crucial determinant in predicting risk of adverse psychosocial outcome.[5] Investigation of this process may reveal the extent and impact of overt and/or covert coercion on both the decision-making process and psychosocial well-being after donation. In the present study, we used standardized instruments to gather preliminary data about how individuals decide to become living kidney donors and how they experience their care and postoperative recovery. An aim of this pilot investigation is to determine the feasibility of obtaining information of this type and the potential value of doing so.

Method

A convenience sample of living kidney donors participated in the study. All kidney donors who had been assessed by the Glasgow Liaison Psychiatry Service were eligible for inclusion in the study. The study was sponsored by National Health Services Research and Development, and ethical approval was obtained from the local research ethics committee. All participants had to provide consent. Patients' demographic information was extracted from medical records. Donors were sent a packet containing information sheets about

the present study, the consent form, outcome measures for completion, and a stamped, addressed envelope to return the documents.

Outcomes

The Donor Decision Control Scale is a 3-item 5-point Likert scale indicating the extent to which donors involved a family member or members in the decision to donate. Level 1 is a decision made independently by the donor; level 2 is a decision made by the donor after consulting with a family member(s); level 3 is a shared decision made by both the donor and a family member(s); level 4 is the donor relying on a family member(s) to make the decision after consulting with the donor; level 5 is the donor relying on a family member(s) to make the decision that the donor will donate. The test-retest reliability for this scale in a prospective study[6] of donor decision making and outcomes was 0.76.

Health-related quality of life with both physical and mental status dimensions was measured by using the SF-36, a 36-item multiple choice and Likert scale instrument.[7] The SF-36 measures 8 health concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to personal or emotional problems, and mental health. Higher scores indicate better health-related quality of life. Normative data have been established for a sample from the United Kingdom; reliability has been reported as 0.92 for the physical status dimension and 0.89 for the mental status dimension. The test-retest reliability for an interval of 2 weeks was 0.89 for the physical status dimension and 0.80 for the mental status dimension.[8]

The Living Donor Survey was used to measure attitude toward living kidney donation, satisfaction with donation education, hospital care, and care after discharge. This instrument comprises 55 multiple choice items and Likert scale questions.[9] In a study[7] of donors' decision making and outcomes, the internal consistency (Cronbach α) of the dimension that measured attitude to living donation was .75.

Results

Forty-three persons were identified as having attended the Glasgow Liaison Psychiatry Service for psychological screening for a prospective kidney donation. Nineteen (44.2%) of them consented to participation and returned the survey. Two of the respondents were excluded from the study because they had eventually not donated. The demographic data for the final sample (N = 17) are summarized in Table 1. One participant did not return a full data set. Absence of data will be made clear throughout reporting as appropriate. The majority (82.3%) of the donors were biologically related to the recipients. Thirteen (76.5%) of the donors were in some form of employment. Four (25%) of 16 participants lived within one of Scotland's most deprived areas.

One participant did not complete the SF-36 adequately for inclusion. The health-related quality of life for the participants is summarized in Table 1. The majority (76.5%) of participants reported involving someone else in the decision-making process. All 10 married donors and 3 (42.9%) of the 7 unmarried donors involved a family member in their decision to donate. Of the married donors who involved someone in their decision to donate, all involved their spouse in the decision. The majority (64.7%) of participants believed that they had made their decision to donate independently. Two (11.8%) shared responsibility for their decision with another person. No participants believed that the decision for them to donate was made by someone else.

The key findings from the Living Donor Survey are presented in Table 2. The majority (93.8%) of participants considered the process of donation to have been explained "very clearly." Similarly, 68.8% and 75.0% of donors described being "very clearly" given general information and information about possible complications, respectively. All participants reported being "very clearly" informed of the risk of death associated with the procedure. The majority (62.5%) of donors considered the pain following surgery to have been "consistent with," "less," or "much less" than their expectations. The majority (56.3%) of participants had a hospital stay that was shorter in duration than they had expected. Most donors did not believe that their lives had been altered since donation with respect to hours worked (85.7%), social activity (93.8%), physical activity (75.0%), mood (81.3%), and sexual activity (86.7%). Most participants indicated they "strongly agree" with the use of living donors (80.0%) and that living donation should be a routine option (66.7%). The majority (64.3%) indicated that they would "strongly encourage" living donation.

The Living Donor Survey includes 2 open-ended questions to canvas patients about their opinion on how the donation process could be improved. Two donors suggested that having an opportunity to speak with previous donors might be helpful in facilitating understanding of the issues of donation. Four patients indicated their belief that donors should receive more information about the recovery process. Specifically, 2 of these patients conveyed a need for more information or support to facilitate muscular rehabilitation. Two participants suggested the process should be shorter in duration, that the workup "took longer than necessary."

Discussion

The present study was designed to assess the feasibility and utility of collecting data related to the psychosocial outcomes of kidney donation and donors'

Table 2 Participants' satisfaction with kidney donation

Aspect evaluated	Response	% of 16 respondents
Explanation of donation process before surgery	Very clear	93.8
	Moderately clear	6.3
Pain after surgery	Much less than expected	12.5
	Less than expected	31.3
	As expected	18.8
	More than expected	31.3
	Much more than expected	6.3
Length of hospital stay	Many fewer days than expected	12.5
	Fewer days than expected	43.8
	As expected	37.5
	More days than expected	6.3
Medical complications after surgery	No	75.0
	Yes	25.0
Medical complications after discharge	No	86.7
	Yes	13.3
Donate again	Strongly agree	93.3
	Somewhat agree	6.7
Pressure was exerted by the transplant team	Strongly disagree	93.3
	Moderately disagree	6.7
Pressure was exerted by the recipient	Strongly disagree	93.3
	Moderately disagree	6.7

any assumptions about the effect of donation on quality of life because psychological adjustment could have occurred in the intervening period. What our results do perhaps indicate is that if donors do experience any difficulties after the procedure, most do not show problematic adjustment to these difficulties.

The majority of donors indicated they involved a family member or friend in their decision to donate, supporting previous reports.[13] Although all such donors stressed that their final decision was made independently, it is not unreasonable to suppose some degree of conscious or unconscious influence of close family members, friends, or indeed the recipients themselves. Given such potential influence it would be prudent to encourage the involvement of identified sources of counsel and support within the workup of prospective donors. Such involvement could facilitate better understanding of the procedure and realistic expectations regarding outcome and postoperative recovery for both donor and family or friend. The measure used to assess the process of donor decision making was limited in both the quantity and quality of information elicited. There could be value in developing more sophisticated measures in an effort to establish some of the social cognitive components implicated in the decision-making process.

An attempt was made to assess the acceptability of the process of kidney donation from the donors' perspective. Generally, donors indicated high levels of satisfaction with all aspects of their contact with the transplant team. The inclusion of 2 open-ended question permitted donors' reporting of aspects of the process that they believed could be enhanced. Comment was given to a broad range of topics; most commonly donors indicated the need for better quality information relating to the postoperative recovery process. Little previous research has addressed that issue. More substantial qualitative research designed to elicit feedback from patients about all aspects of the donation process could provide valuable insights into how services could be appropriately designed to meet the needs of this population.

Limitations

The current investigation used a convenience sample to pilot the use of methods designed to elicit information on the outcome of transplant donation. The number of donors who consented to the study was insufficient to derive any firm conclusions regarding the generalizability of the findings. The study was a retrospective pilot investigation that included persons who had donated up to 3 years earlier. This study provides useful information about long-term outcomes of kidney donation. However, retrospective recollection is recognized as unreliable and subject to recall bias.

The present study had a healthy response rate to postal questionnaires. However, this self-selecting group may be a potential source of bias. For example, those who experienced positive outcomes after donation may have been more likely to respond. A methodological

Table 1 Participant characteristics (number of participants [%] for categorical data; median for ordinal data; mean ± standard deviation for continuous data)

		Value
Sex, No. (%)	Male	9 (52.9)
	Female	8 (47.1)
Age, mean (SD), y		44.37 (11.62)
Time passed since donation, mean (SD), months		1.86 (0.97)
Ethnicity, No. (%)	White, Scottish	13 (76.5)
	White, other British	1 (5.9)
	Missing	3 (17.6)
Employment status, No. (%)	Full-time employment	11 (64.7)
	Part-time employment	2 (11.8)
	Retired	2 (11.8)
	Other	2 (11.8)
Relationship of recipient to donor, No. (%)	Spouse	3 (17.6)
	Son/daughter	3 (17.6)
	Parent	1 (5.9)
	Sibling	7 (41.2)
	Other relative	3 (17.6)
Martial status, No. (%)	Married	10 (58.8)
	Single	2 (11.8)
	Cohabiting	1 (5.9)
	Separated	1 (5.9)
	Divorced	2 (11.8)
	Widowed	1 (5.9)
Scottish Index of Multiple Deprivation rank,[a] median		2012.50
SF-36 score,[a] mean (SD)	Physical functioning	93.13 (15.04)
	Role, physical	94.53 (11.61)
	Bodily pain	84.72 (20.64)
	General health	83.13 (14.10)
	Vitality	71.48 (19.49)
	Social functioning	86.72 (19.62)
	Role, emotional	95.83 (12.91)
	Mental health	81.56 (12.07)

[a] Only 16 of the 17 participants provided data for this item.

process of decision making. It was hoped that the results elicited from this investigation could be used to inform the design and application of a larger scale prospective study to investigate donors' psychosocial well-being.

The study relied on a historical convenience sample that offered a limited population from which to recruit. The response rate (~40%) was encouraging and suggests that patients are interested in participating in studies of this nature. The reasons for nonparticipation are unclear. However, it is perhaps reasonable to assume low motivation or interest to participate given the length of time elapsed since donation in some instances. It is anticipated that recruitment will be more successful if patients are informed of the study during their workup when the relevancy of such an investigation should be at its most obvious. Researchers in earlier studies that used prospective designs have reported excellent rates of recruitment and retention.[10]

Donor's health-related quality of life was a primary outcome measure of the current study. Consistent with pervious research,[11] our results suggest higher levels of quality of life on all dimensions compared with population norms.[12] This cross-sectional finding is limited by the absence of data documenting the change in psychosocial well-being as the donation process progressed. Measures of aspects of psychosocial functioning, including health-related quality of life, before donation would permit meaningful comparison of scores in this regard. Data collected throughout the donation process would reveal any change in such outcomes and foster an understanding of the true impact of donation on variables of this nature. Additionally, it would allow scrutiny of the mechanisms underlying any change in this regard or facilitating adjustment to the surgery.

The mean time since donation in the present study was almost 2 years. It is therefore difficult to make

weakness is the absence of key characteristics of the donors who did not participate, which would have enabled between-groups comparison. Further, an absence of specific measures of psychological well-being denied the opportunity to describe the populations' adjustment in this regard and correlate outcomes to psychosocial characteristics.

Conclusions

It was hoped that the experience of this pilot investigation would both demonstrate the feasibility of working with this unique population and inform the design of a larger scale prospective investigation. Our results suggest that this population is both willing and able to report on a number of outcomes pertaining to the process of kidney donation.

Possibilities regarding the extension of this pilot investigation are numerous. Data regarding the psychosocial well-being of donors should be collected routinely throughout the donation process. Prospective collection of data before donation would allow the direct comparison of outcomes before and after donation. A variety of demographic and psychosocial variables could be considered as predictors of outcome. This might incorporate aspects of the decision-making process. However, further more substantial prospective studies are required to determine what these factors are and the true extent of their influence. Any findings in this regard would help in the development of evidence-based screening tools for the psychological assessment of prospective donors, which could meaningfully contribute to the identification of candidates at an increased risk of poor adjustment after donation.

Financial Disclosures

None reported.

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APPENDIX 6: ETHICS APPROVAL LETTER

WoSRES
West of Scotland Research Ethics Service

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22 October 2009

Mrs Yvonne McNeill
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Dear Mrs McNeill

Study Title: **THE STUDY OF LIVING KIDNEY DONOR DECISION-MAKING AND PSYCHOSOCIAL OUTCOMES.**
REC reference number: **09/S1001/65**
Protocol number: **Version 1**

The Research Ethics Committee reviewed the above application at the meeting held on 21 October 2009 in your absence.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is

available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

The Committee require some amendments/clarifications to the Study Design and Participant Information Sheet as follows :

Study Design

a. Question A36 Access to medical records box to be ticked

Participant Information Sheet

a. The Committee are of the opinion that the questionnaire should be sent out to participants after signed consent has been received
b. Will a 3 month questionnaire be sent out to participant if the transplant has been unsuccessful?
c. Will the consent form and questionnaire be collated by the transplant coordinator?
d. The Committee are seeking reassurance that any untoward information that shows on the questionnaire will be sent to the transplant coordinator
e. The Participant Information Sheet and Consent Form should have the full title of the study as a header
f. The beginning of the Participant Information should a brief introduction about the Chief Investigator
g. The Participant Information Sheet should be invitational

The above amendments/clarifications to come back to the Vice Chair and Coordinator for checking and filing

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering Letter		01 October 2009
REC application	2.3	01 September 2009
Protocol	Version 1	01 October 2009
Investigator CV		01 September 2009
Participant Information Sheet	Version 1	01 October 2009
Participant Consent Form	Version 1	01 October 2009
Letter from Sponsor		23 September 2009
Summary/Synopsis	Version 1	25 September 2009
Questionnaire: Validated - COPE		
Questionnaire: Validated - SF36		
Questionnaire: Validated - Donor decision control scale		
Questionnaire: HADS		
Questionnaire: Living Donor Survey		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S1001/65	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

[redacted]

Mrs L Tregonning
Vice Chair

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CHAPTER 3: ADVANCED CLINICAL PRACTICE I (COURSE 12):REFLECTIVE CRITICAL ACCOUNT

Title: Learning to be mindful of negative automatic thoughts and their impact on behaviour in an anxiety provoking situation: Abstract

Abstract

This reflective account describes a time in which I presented to a group of medical students and was challenged by an Assistant Psychologist. Giving the presentation showed my supervisor and myself that I had the ability to present to other professionals and therefore meet an advanced competency for the placement. However the process of reflecting on this event provided the most valuable learning experience. Using Gibbs' (1988) model of reflection, in this account I will detail my reflection during and after the presentation. Through this reflection I have learnt to be more mindful of my negative automatic thoughts and the impact that they can have on my behaviour and emotions. I learnt to understand others' behaviour by making hypotheses about their thoughts and emotions. This reflection has better prepared me for becoming a newly qualified practitioner as I have learnt that I cannot change the behaviour of other professionals that I work with but I can behave in an assertive and professional manner whilst gathering evidence which undermines negative thoughts about my ability. I therefore feel more confident in my ability to implement the Continuing Professional Development guidelines which state that clinical psychologists should work with other professionals from their own and other agencies in order to meet the complex needs of their clients.

CHAPTER 4: ADVANCED CLINICAL PRACTICE 2 (COURSE 13): REFLECTIVE CRITICAL ACCOUNT

Learning to adapt clinical practice to meet the needs of ethnic minority communities to overcome health inequalities and to develop advance clinical competencies: **Abstract**

ABSTRACT

My second advanced clinical placement was within a Clinical Health Psychology Service which offered rehabilitation following a specific chronic illness (for confidentiality reasons the exact nature of the condition is not disclosed). It was widely accepted that South Asians living in the UK had a higher prevalence of this condition (British Heart Foundation, 2003) but were less likely to engage with the appropriate rehabilitation services (Webster, 1997) . Government legislation stipulates that NHS Scotland must meet the needs of people from different cultural backgrounds (Race Relations Act 2000) and therefore the clinicians and the managers in this team were focused on developing the service to overcome this health inequality.

Currently the Government is focusing on the provision of mental health services in order to achieve race equality in the NHS (Delivering Equal Services to Black and Minority Ethnic Communities in Scotland – Proposal for a Race Equality & Mental Health Programme: 2008-2011). The National Occupational Standards (NOS) state that Clinical Psychologists must manage the provision of psychological systems, services and resources to meet customer requirements. Therefore as a Clinical Psychologist and as a member of this team, I had a responsibility to offer a service that met the needs of individuals from an ethnic minority culture.

In this account I have used Kolb's Learning Cycle (1984) and Gibbs' Model of Reflection (1988) to explore how I developed my competency in working with individuals from minority ethnic

communities through reflecting on my professional experience and the literature that I read. I reflect on how in an attempt to show an understanding and respect for a Muslim patient's culture and faith I initially failed to use my core competencies in developing a therapeutic relationship, carrying out an assessment and establishing the patient's thoughts and beliefs through Socratic questioning. However, though reflection-in-action and reflection-on-action I was able to go on to encourage my patient to engage with a service which she previously refused to engage in and provided a full course of Narrative Therapy with a planned discharge.